Distribution Agreement

Signature:

Kristina Celeste Fong	Date

Using Patient Perspectives to Analyze the Ethical Implications of Identity during Deep Brain Stimulation for Treatment Resistant Depression

By

Kristina Celeste Fong
Master of Arts

Bioethics

Karen Rommelfanger, Ph.D.
Advisor

Andrea Crowell, M.D.
Committee Member

Paul Root Wolpe, Ph.D.
Committee Member

Accepted:

Lisa A. Tedesco, Ph.D.
Dean of the James T. Laney School of Graduate Studies

Date

Using Patient Perspectives to Analyze the Ethical Implications of Identity during Deep Brain Stimulation for Treatment Resistant Depression

By

Kristina Celeste Fong
B.S., The University of Alabama at Birmingham, 2017

Advisor: Karen Rommelfanger, Ph. D.

An abstract of
A thesis submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
in partial fulfillment of the requirements for the degree of
Master of Arts
in Bioethics
2019

Abstract

Using Patient Perspectives to Analyze the Ethical Implications of Identity during Deep Brain Stimulation for Treatment Resistant Depression

By Kristina Celeste Fong

Deep brain stimulation (DBS) has emerged as a potential therapy for individuals with treatment resistant depression (TRD). However, its use has been ethically controversial, with concern about the potential harm that it may have over its potential benefits. One such concern at the forefront of debates is its impact to concepts of identity. Many scholars have responded to the ethical concerns surrounding DBS for depression, though there are few of these studies that are supported by empirical evidence, especially as they relate to identity. This project has the means to collect this empirical evidence that is scarcely found in ethics literature. As such, this thesis will investigate how patient experiences with DBS for depression affect notions of identity, and how these might influence decisions to become involved with this experimental therapy. Five themes emerged from the analysis of patient perspectives: well-unwell distinction, control, narrative, relationship to others, and perception. These themes provide insight into the relationship between identity, DBS, and depression and assist in promoting a framework of identity to adequately respond to current ethics discussions regarding DBS for depression research.

Using Patient Perspectives to Analyze the Ethical Implications of Identity during Deep Brain Stimulation for Treatment Resistant Depression

By

Kristina Celeste Fong
B.S., The University of Alabama at Birmingham, 2017

Advisor: Karen Rommelfanger, Ph. D.

A thesis submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
in partial fulfillment of the requirements for the degree of
Master of Arts
in Bioethics
2019

Table of Contents

Tables and Figures

Introduction

Deep brain stimulation (DBS) has been used to treat a variety of brain-based disorders by modulating the activity of specific areas of the brain through electrical stimulation. Currently, DBS is used as a therapy for some neurological disorders, the most common of these being Parkinson's disease. However, there have been proposals on the effectiveness of DBS for psychiatric disorders like depression, where a small number of these have led to research studies investigating the clinical benefit of DBS for treatment resistant depression at different target sites (Fenoy et al., 2018; Jimenez et al., 2005; Malone et al., 2009; Mayberg et al., 2005; Sartorius et al., 2010; Schlaepfer et al., 2008).

Depression is the most prevalent psychiatric disorder and the fourth leading cause of disability worldwide (Kessler & Bromet, 2013). Despite many therapeutic strategies available to assist in managing depressive symptoms, there are a significant number of cases that are resistant to treatment (Berlim & Turecki, 2007). For many who have treatment resistant depression (TRD), managing the disorder is difficult. While deep brain stimulation has demonstrated the potential to treat TRD, there are significant concerns regarding not only its efficacy, but also its ethics.

One such ethical concern regarding the use of DBS for depression is its impact on identity and resulting implications for behavior, agency, decision-making, etc. (Delaloye & Holtzheimer, 2014; Lipstman & Glannon, 2013). The issue arises from the potential side effects of DBS, which may cause functional changes within the patient's brain that could negatively impact his or her sense of self or identity. Many scholars have responded to the ethical concerns surrounding DBS for depression, though there are few of these studies that are supported by empirical evidence, especially as they relate to identity. Instead, there are a number of assumptions about identity in DBS for depression that are primarily based on theoretical arguments (Baylis, 2013; Glannon, 2008; Johansson et al., 2011). However, if we are to adequately review and respond to ethical concerns about identity, which help guide risk-benefit analyses, empirical evidence investigating how notions of identity might be affected during DBS for depression must be provided.

Aims, objectives, and research questions

This thesis is an analysis of the relationship between identity, depression, and DBS. Although many theoretical and empirical studies have been conducted to analyze the ethics of DBS for motor disorders like Parkinson's, there is a particularly limited amount of empirical work investigating the ethics of DBS for depression, especially as it relates to identity. This is in part due to a lack of clinical research studies on DBS for depression and, as a result, little empirical evidence to analyze its ethics from.

This project has the means to collect this empirical evidence that is scarcely found in ethics literature. With access to a clinical research study investigating the clinical effectiveness of DBS for TRD, I can utilize the unique perspectives of research participants to examine and respond to current ethics discussions on DBS for intractable depression. This thesis will investigate how patients' experiences with DBS for their intractable depression affect notions of identity, and how these might influence decisions to become involved with this experimental therapy. This will be done by establishing themes related to identity that assist in providing insight into the relationship between identity, DBS, and depression.

In pursuing this investigation, it will be important to keep in mind two research questions:

1) What are patients' perspectives on depression and how it influences their concepts of identity?
2) How do patients perceive any identity changes that occur as a result of DBS for depression?

Keeping these questions in mind as we pursue our analysis, this thesis will be structured into two major sections. In section one, I will first provide a brief background to depression, deep brain stimulation, and any relevant features of identity, as this information will be necessary to understand the research focuses of this project and move forward with data analysis, coding, and theme creation. This will be followed by a literature review of the current perspectives on the ethics of deep brain stimulation as it affects concepts of identity. This section will be divided further as we discuss the identity features of personality, self-identification, identification with others, and agency and responsibility. The same will be done for deep brain stimulation for depression, focusing primarily on identity as it relates to informed consent processes and decision-making capacity. Section two focuses specifically on my research project, first by reviewing its research design, significance, and methodology. The resulting identity related themes that emerged from the analysis will be introduced and analyzed at it relates to the ethics of DBS for depression. Finally, this thesis will close with the its limitations and impetus for future work.

Background

What is major depressive disorder?

Major depressive disorder (MDD), is a highly prevalent and debilitating psychiatric disorder. In the U.S. alone, a national survey found that 7% of adults over the age of eighteen and 13% of adolescents experienced at least one major depressive episode during 2017, with 65% of these adults and 71% of adolescents citing severe impairment and difficulty in home, work, or social life because of their depression (National Institute of Mental Health, 2018). Depression is most commonly recognized by a period of reduced mood and loss of interest or pleasure, although a formal diagnosis is more complex since depression can manifest through a variety of clinical symptoms and signs (Fava & Kendler, 2000).

The DSM-V, the diagnostic manual for psychiatric disorders, defines the diagnostic criteria for major depressive disorder. To highlight the complexity that is present in identifying and diagnosing MDD, an overview of its clinical symptoms is quoted below from the DSM-V.

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

   1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, hopeless) or observation made by others (e.g., appears tearful). (**Note:** In children and adolescents, can be irritable mood.)
   2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).

3. Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day. (**Note:** In children, consider failure to make expected weight gain.)
4. Insomnia or hypersomnia nearly every day.
5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
6. Fatigue or loss of energy nearly every day.
7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The episode is not attributable to the physiological effects of a substance or another medical condition.

D. The occurrence of the major depressive episode is not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified and unspecified schizophrenia spectrum and other psychotic disorders.

E. There has never been a manic episode or a hypomanic episode.

(American Psychiatric Association, 2013)

Treatment resistant depression and a new potential therapy

Once an MDD diagnosis has been made, there are several treatment options available, including more than 21 FDA approved antidepressant medications, psychotherapy, and, for more persistent cases, electroconvulsive therapy (ECT) (Armstrong, 2011; National Institute of Mental Health). However, treatment routes for many individuals with depression remain complex. It is estimated that more than half do not respond to the first therapy provided, and as many as 20% of patients will have some degree of treatment resistance, although this percentage has gone as high as 33% in some sources (Berlim et al., 2008; Fava, 2003; Keller et al., 1992). What constitutes treatment resistance with respect to medication doses or duration and type of non-response is not agreed upon and different sources note different conditions for TRD diagnoses (Berlim & Turecki, 2007). Further, there is no clinical consensus on diagnoses of treatment resistance with the number of failed therapies, as sources can vary between two to four, or combination of therapies. Patients experience treatment resistance at varying degrees. Some may have no response with certain medications, while others may find medications that work in reducing depressive symptoms for a period of time before they stop working altogether (Berlim & Turecki, 2007; Souery et al., 2006).

Depression can have negative impacts on quality of life with significant impairment in social or occupational function (American Psychiatric Association, 2013). A review of research studies investigating the relationship between depression and quality of life found a negative correlation, where lower quality of life corresponded to greater severity of depressive symptoms (Berlim and Fleck, 2007). As a result, given the significantly high population of people living with depression, it will be necessary to find effective therapies for those diagnosed with TRD.

Deep brain stimulation (DBS), most well-known for its use in Parkinson's disease, has emerged as a potential therapy for individuals with intractable depression, with several brain regions having been identified as potential target sites (Anderson et al., 2012). In 1999, Mayberg et al. implicated the subgenual cingulate region of the brain (Brodmann area 25) in the modulation of negative mood states associated with sadness and depression (Mayberg et al., 1999). It was later proposed that DBS could be beneficial in effectively mediating depressive symptoms in those with treatment resistant depression (Mayberg et al. 2005).

What is deep brain stimulation?

Deep brain stimulation is a neurotechnology that includes the administration of electrical stimulation to a particular area of the brain via implanted electrodes connected to a power source. Simply put, applying electrical stimulation to a specific region in the brain effectively changes the functioning of that region by modulating its neurological activity (Delaloye & Holtzheimer, 2014). When applied clinically, DBS can be used to mitigate the clinical symptoms of neurologically based disorders.

The use of electrical stimulation has been essential in investigating brain function since the 19th century (Perlmutter and Mink, 2006). Since then, we have been better able to implicate organ structures and regions to functions and have demonstrated deep brain stimulation's therapeutic potential for a variety of disorders like Parkinson's, epilepsy, obsessive compulsive disorder, and depression. DBS is best known for treating motor disorders like Parkinson's disease (Tekriwal & Baltuch, 2015). The stimulation of different regions associated with the disease alter the neuronal activity of those areas, which in turn can reduce symptoms like limb tremor (Kumar et al. 2003, Putzke et al. 2003) or dyskinesia, a side effect of long-term use of dopaminergic medications (Anderson et al. 2005, Peppe et al. 2001). Further, the treatment of different motor and psychiatric disorders can be done by moving the stimulation sites to other areas of the brain. With regard to psychiatric disorders, DBS has been provisionally approved for Obsessive Compulsive Disorder (OCD), although it remains an experimental therapy for cases of depression.

Generally, the use of deep brain stimulation has raised a number of ethical concerns, with particular attention to potential harms that it may cause over its benefits. With regard to depression, specifically, there is not enough evidence to make a reasonable claim that the potential clinical benefit could outweigh any potential risks, such as those to identity. The following section provides a review of the previous work, which will help frame the case for this project. However, I will first build from existing literature a practical understanding of identity as it is beneficial to the data analysis. Following this, I will examine the ethics of DBS as a neurotechnology on its own, before delving into the ethical nuances of DBS and its application for treatment resistant depression.

Literature Review

What is Identity?

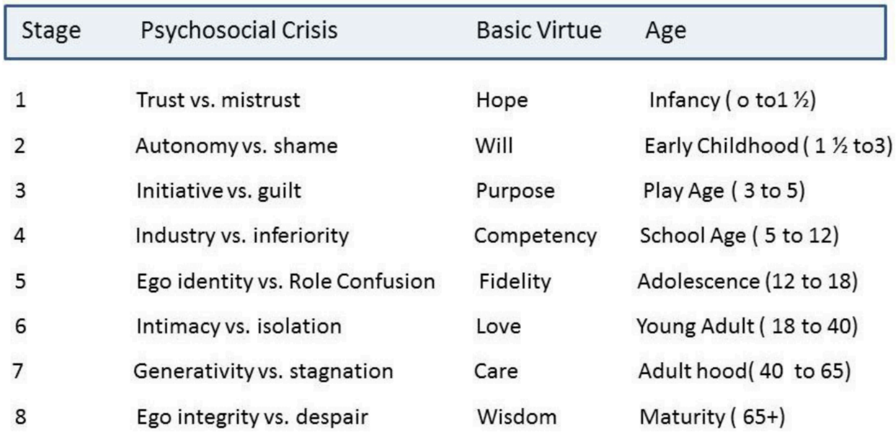
In the broadest sense, identity can be expressed as who a person is, or rather, what makes a person recognizable as being him or herself. Psychologist, Daphna Oyserman and colleagues provide a summarizing statement on some key features that encompass identity, which I will break down throughout this section.

> “Identities are the traits and characteristics, social relations, roles, and social group memberships that define who one is. Identities can be focused on the past-what used to be true of one, the present-what is true of one now, or the future-the person one expects or wishes to become, the person one feels obligated to try to become, or the per son one fears one may become. Identities are orienting, they provide a meaning-making lens and focus one's attention on some but not other features of the immediate context”
>
> (Oyserman et al., 2012).

Identity is also a rather an ambiguous concept, complicated by the fact that it has perhaps been overused in many different contexts for many different purposes (Buckingham, 2008). James Fearon explains that “our present idea of ‘identity’ is a fairly recent social construct... even though everyone knows how to use the word properly in everyday discourse, it proves quite difficult to give a short and adequate summary statement that captures the range of its present meanings” (Fearon, 1999). Despite this lack of consensus on what “identity” means, many academics have studied identity in an attempt to understand its value. Together, these theories of identity can be used to gain a better understanding of it in a practical sense.

Erikson’s psychosocial stages of identity

Most of our contemporary understanding of identity comes from the work of psychologist and psychoanalyst Erik Erikson during the mid-20th century. Much of his work focused on youth identity formation and crisis. However, in doing so he was able to build his theory on the different characteristics that help with identity formation as we age. Erikson's psychosocial development theory was rooted in the social, emphasizing the role of culture and society on sense of self. He proposed that identity was formed through psychosocial conflicts that occur through various stages of life. In each stage, two conflicting forces are identified based on specific life-stage challenges. If the individual is able to successfully resolve the conflict, the most favorable outcome will be the acquisition of a particular virtue, or strength, that will ultimately contribute to a healthy personality and established sense of identity (McLeod, 2008). While these conflicts are organized into specific life stages, they reappear and can be reestablished or modified over time (Erikson, 1956). These stages have been summarized below in Table 1.



Stage	Psychosocial Crisis	Basic Virtue	Age
1	Trust vs. mistrust	Hope	Infancy (o to1 ½)
2	Autonomy vs. shame	Will	Early Childhood (1 ½ to3)
3	Initiative vs. guilt	Purpose	Play Age (3 to 5)
4	Industry vs. inferiority	Competency	School Age (5 to 12)
5	Ego identity vs. Role Confusion	Fidelity	Adolescence (12 to 18)
6	Intimacy vs. isolation	Love	Young Adult (18 to 40)
7	Generativity vs. stagnation	Care	Adult hood(40 to 65)
8	Ego integrity vs. despair	Wisdom	Maturity (65+)

Table 1. Eight psychosocial stages of identity development, theorized by Erik Erikson in his works (Erikson, 1959) (McLeod, 2008).

Criticism of Erikson's work question the actuality of the discrete stages of personality development that he suggests (McRae & Costa, 1997), while others criticize his work for its vagueness in writing and concept of identity (Hoare, 2002). However, Erikson's theory of identity has been influential for a number of research studies (Kroger, 2007). It placed particular importance on the value that social environment had on personality development, while also acknowledging a changing nature to identity, developing as new environments, experiences, and conflicts emerged through the entire lifespan.

Before we continue, it will be important to clarify usages of "identity," "self," and "self-concept as it will be relevant to this project. As evidenced by criticisms of Erikson's vague language in his works, he fails to fully elaborate on his meaning behind the use of "identity." Further, he uses identity and self-concept synonymously, while, in other sources, identity can also be used to make sense of some aspect or part of self-concept (Oyserman et al., 2012). For the purposes of this project, unless further specified, "identity" and "self" will be used interchangeably. This is because this project directs focus to the personal perspectives of research subjects, whose concepts of identity and self will be discussed with similar usages. Mentions of "self-concept" that are used in this background section refer specifically to how one perceives oneself to be. Where "identity" and "self" can be used in more objective meanings, "self-concept" is entirely subjective to an individual.

Dual nature of identity

There is an overwhelming sense of duality to identity. Apart from the psychosocial conflicts that Erikson describes, identity also requires a balance between similarity and difference, individual and group. David Buckingham writes of this duality, "identity is unique to each of us that we assume is more or less consistent (and hence the same) over time... yet on the other hand, identity also implies a relationship with a broader collective or social group" (Buckingham, 2008). Consequently, there continues to be an inherent tension in navigating one's own identity amid the desire to accept and endorse being a unique product of biology and experience, while also finding and maintaining relationships among others on the basis of social, cultural, and biological characteristics, as well as through common values, experiences, and interests (Buckingham, 2008). To further this notion of duality, social psychology and sociology literature tend to characterize identity theory through two separate, yet intertwined constructs: a social and a personal construct (Fearon, 2009).

Social Identity

Role identification

The social construct of identity is dependent on role identification. In general, society both dictates and is dictated by the social roles that individuals in that particular society hold (Stets and Burke, 2012). Identity is thought to be comprised of the collective grouping of roles that individuals are characterized by, where different role identities are distinguished by particular features or attributes. Such examples of social roles include female or male, parent, student, scientist, friend, etc.

To social identity and identity theorists, these role identities reflect association with particular social categories, characterized by specific membership rules. These rules are understood in terms of either a set of characteristics thought to be associated with typical members of said role, or the behaviors often expected or required by members in particular instances (Fearon, 1999). Many times, a certain role is accompanied by a complementary role that another person holds (Oyserman et al., 2012). For example, a sick role holds the expectation that an individual is somehow incapacitated by an illness or disease, which often necessitates someone else to hold the complementary role of caregiver, who, as the name suggests, is expected to behave in ways that care for the sick individual. These roles are characterized by shared understandings and expectations and have defined traits, characteristics, attributes, goals, and values. For some roles there are recognized procedures or certifications that they encompass, like a physician having a medical degree and a license to practice, while other role memberships can be less formal, although still dependent on social conventions, such as that of a caregiver.

Role identities are defined by social circumstances and environments. As such, it is likely for individuals to associate themselves with memberships in multiple roles, where their definitions of identity might be dependent on either the particular contexts of questions or the situation they find themselves in at the time. Collectively, though, these role identities constitute the overall self. Identity is contingent on the "categorization of the self as an occupant of a role, and incorporating into the self, the meanings and expectations associated with the role and its performance" (Stets and Burke, 2000). Thus, social roles are of great value to one's sense of self. There is evidence that holding more roles has greater positive influences on mental health (Thoits, 2003) and that greater psychological well-being leads to the acquisition of more role identities, particularly those that encompass more voluntary or charity work (Thoits & Hewitt, 2001).

Identity negotiation and self-concept

Like the name implies, the social identity is rooted in the social. Just as Erikson's psychosocial stages relies on the premise that individuals cannot be understood apart from their social contexts (Erikson, 1959), more modern scholars acknowledge that the development of self and what individuals do greatly depends on the society in which they live in (Kehily, 2009; Stets and Burke, 2012). Since the social environments that people find themselves in are expected to change as they go through life, it is essential for them to continually develop and redevelop their role identifications and behaviors according to these changes. This "reflexive capacity" is a fundamental process of identity and selfhood (Kehily, 2009; Oyserman et al., 2012; Stets and Burke, 2012).

Humans, capable of rationality and agency, have the ability to socially interact with others and, as a response to these interactions, reflect upon and re-evaluate themselves in order to bring about desired future states (Stets and Burke, 2012). They are also able to self-reflect by forming direct comparisons with those they interact with, seeing "identity as relational," established and re-established according to their relationships with others who are similar and other who are different (Kehily, 2009). As a result of this constant process of identifying and understanding relationships with ourselves and others, we are able to build a view of who we think we are. That is, our self-concept, defined as "the set of meanings we hold for ourselves when we look at ourselves, or inferences about who we are…our wishes and desires, and our evaluations of ourselves" (Stets and Burke, 2012). The reflexivity of self-concept allows for us to relate current perceptions of ourselves to the beliefs and practices we wish to have and engage in. In other words, who we are versus who we want to be and what we want to do.

Personal Identity

Me versus we

The second construct of identity is the personal identity. Generally, less is defined or deduced by this sense, and as a result, there is some uncertainty about a general understanding of personal identity. Oyserman et al. simply define personal identities as those that "reflect traits or characteristics that may feel separate from one's social and role identities" (Oyserman, 2012). From this, one can envision the personal aspects of identity as necessarily distinguishable from the social. However, it seems that it is not a precise enough to claim that personal identity has stake over all other traits, characteristics, goals, values, etc. that are not derived from social identities. Therefore, Stets and Burke go further to say that the categorization of personal identities is contingent on “seeing the self as distinct and different from others” (Stets and Burke, 2012). This can be taken to mean that what defines the personal features of the self are not only “personal” versus “social” aspects, but also based on “me” versus “we.” The personal sense means to emphasize some aspect of individuality and is also more closely intertwined with self-concept. James Fearon, a political scientist, in his efforts to promote an interdisciplinary framework of identity theory into applied research for political science and international relations discourse, has managed to combine these features of personal identity into a basic statement with three components:

> “Personal identity is a set of attributes, beliefs, desires, or principles of action that a person thinks distinguish her in socially relevant ways and that (a) the person takes a special pride in; (b) the person takes no special pride in, but which so orient her behavior that she would be at a loss about how to act and what to do without them; or (c) the person feels she could not change even if she wanted to.”
>
> (Fearon, 1999)

The social and personal identities that we think of as “me” versus “we,” refer back to the idea that identity is a balance between what makes one similar to others (social identity) and what makes us different (personal identity). Both are established by a set of traits, behaviors, goals, values, etc., but it can be thought that the differences between them are contingent on whether these characteristics are derived from the group standard or the individual standard (Stets & Burke, 2012).

Psychological continuity and the issue with identity

The confusion with personal identity begins with the name: *personal*. It insinuates something about identity as somehow reaching to the essence of a person's identity. As Fearon explains, "the problem of explaining what personal identity is (as we talk about it) is the problem of stating what aspects of a person it refers to and precisely in what sense these are important or "essential" (Fearon, 1999). There is a nature about "personal" that leads us to attempt to understand that aspect of identity as some sort of fundamental nature or component about persons in that if it were to be missing, we would cease to remain ourselves.

This issue reaches closely to the one key question of identity that many philosophers pose: what makes someone at one point in time the same individual at another point? These philosophical questions about identity all allude to a sort of unchanging characteristic that is essential or fundamental in defining someone as being him or herself.

Perhaps one of the more classic identity theories holds that personal identity is a matter of psychological continuity. The psychological continuity theory of identity posits that what connects a person at two different points in time is that the later identity is "psychologically continuous" with the earlier one (Olson, 2017). Philosopher John Locke originally proposed that identity was dependent on a consciousness bound by memories (Locke, 1689). Critiques have questioned the thesis that memory is what makes someone the same person over two points in time, especially given that we now know memories can be easily influenced or made entirely false (Loftus & Pickrell, 1995). We remain inclined, though, to hold onto the perspective that psychological characteristics are critical to identity and the persistence of self (Nichols and Bruno, 2010). Thus, extended theories have emerged suggesting that identities develop and redevelop through repeated self-identification, done by integrating autobiographical memories into an overarching life narrative, the temporal relations that connect one psychological state to (Fivush, 2011; Schechtman, 2010).

Critical interests

Other psychological components beyond personal experiences and memory include beliefs, desires, intentions, etc. These have shown potential for registering as components of the personal sense of identity that Fearon was alluding to. For example, Ronald Dworkin argues that such interests that people find essential to their understanding of what produces a good life are "critical interests," which hold more relevance to the personal sense of identity than "experiential interests." Though good experiences contribute to an enjoyable life, critical interests dictate what values and desires we strive to make reality for ourselves in order to form a more meaningful life (Dworkin, 1993). These interests are constant throughout time and exist to help us create a continuous narrative that we identify as a personal identity.

Self-dignifying characteristics

> *"Personal identity is a set of attributes, beliefs, desires, or principles of action that a person thinks distinguish her in socially relevant ways and that (a) the person takes a special pride in…" (Fearon, 1999)*

Returning to Fearon's definition of personal identity, the first element in his definition is a characterization of oneself that one takes special pride in. In other words, an element of self that someone sees as particularly unique and integral to his or her self-esteem. Used in this respect, this sense of identity is a "partial and indirect substitute for 'dignity,' 'honor,' and 'pride'" (Fearon, 1999).

We generally want to think well of ourselves and, as such, are keen to identify ourselves by the characteristics we find dignity in and that bolster our self-esteem. Some features of ourselves that fall into this category are related to our sense of morality, hence our personal association with our beliefs, desires, or principles. Philosopher Charles Taylor has argued that personal identity serves as a moral framework for action bound by moral principles, ends, and goals.

> "My identity is defined by the commitments and identifications which provide the frame or horizon within which I can try to determine from case to case what is good, or valuable, or what ought to be done, or what I endorse or oppose."
>
> (Taylor, 1989)

Morality is often seen as an important part of one's sense of self and ought to be something that one takes great pride in. This makes sense for why identity is such a strong motivator of action. We tend to behave in ways that are dictated by our beliefs of how we ought to act in certain situations because those actions are most likely to reinforce those characteristics about ourselves that we are most proud of.

However, other characteristics beyond those related to morality can be reasonable claims of personal identity. We accept that persons can be defined by attributes such as physical traits, social roles, personal goals, desires, or preferences. For example, I can consider my red hair or tall height, both physical traits, to be a major part of my identity because it is unique and I take pride in that physical aspect of myself. In another instance, I could consider my Asian ancestry or occupation as a teacher, both also defining social categories, to be key a facet of my personal identity because, again, I take great pride in my membership in these roles. These characteristics are not bound by normative frameworks and can be used to express personal identity provided that it is seen as an important source of pride and distinction as an individual.

Consistent characteristics

> *"Personal identity is a set of attributes, beliefs, desires, or principles of action that a person thinks distinguish her in socially relevant ways and that…(b) the person takes no special pride in, but which so orient her behavior that she would be at a loss about how to act and what to do without them…" (Fearon, 1999)*

Just as some behaviors are guided by the rules or frameworks of social roles and memberships, some are driven by the desire to improve self-esteem or pride in the aspects of identity that we find personally special (Fearon, 1999). Persons are not only defined by those things that they are proud of, though. Fearon's second stipulation of personal identity states that we can be defined by aspects of ourselves that orient our behavior, even if they provide us with no source of pride or obvious moral direction (Fearon, 1999). If I am someone who spends my Saturdays going to the movies, then I might be defined as being someone who is unavailable on Saturdays because I am at the local theater. Going to the movies every weekend can have nothing to do with my moral beliefs. It might not be anything I take great pride in; I could be spending my Saturdays partaking in something viewed to have greater moral value, like charity work. But I continue going to the movies because it is what I have always done. My actions on Saturday are defined by my actions from the previous Saturday, and if the local theater experienced a power outage that prevented me from going to watching a movie, I would suddenly find myself lost as to what I might do with my Saturday.

Fixed characteristics

> *"Personal identity is a set of attributes, beliefs, desires, or principles of action that a person thinks distinguish her in socially relevant ways and that…(c) the person feels she could not change even if she wanted to" (Fearon, 1999)*

Fearon's final stipulation to his explanation of personal identity finds that aspects of persons that define who they are includes unchangeable fixtures that, regardless of one's perception of it or attempts at changing it, remain a part of identity. Drawing relevance from this project let us say, for example, that I am someone who has depression. No matter how hard I try, I cannot *not* be someone who has depression. To an extent, I might even be ashamed that I suffer from depression, but no matter what it is a part of my identity. Even if I am not currently in a depressive episode, being someone with a diagnosis of depression is a feature of my identity that can affect my experiences, guide how I behave, or impact the things that I find value in.

There are several concepts of identity, all with their own working definitions. Fearon provides a good explanation of the personal sense of identity that helps to form a working understanding of it. Despite identity's inherent complexity, we do not need to have figured out entirely the mystery behind it in order to understand its value. Ultimately, identity is a subjective concept with different meanings for different people. In some respects, our sense of identity is entirely our own, subjective to our experiences and interpretation. My concept of self may not be the same as anyone else's, but this absence of universal understanding does not discount the value that it has for me.

Ethical considerations in deep brain stimulation

DBS is unique for its effectiveness and versatility. As such, it has been considered as a potential therapy option for a number of neurological disorders. However, its exact mechanism of action and resulting effect on neuronal activity is not well understood. DBS requires an expensive and invasive procedure to implant electrodes in the deep structures of the brain and a battery under the skin in the chest. The stimulation can produce both expected and unexpected results, and there are a number of potential side effects that can occur (Kraemer, 2013). As such, DBS is generally reserved for patients who have experienced serious complications with or are resistant to other forms of treatments.

Neurotechnologies, like deep brain stimulation, that alter or influence brain function raise a range of ethical concerns, such as issues related to the ethics of normality, responsibility, agency, and informed consent, to name a few (Klein et al., 2015). These matters are often intertwined with one another. Identity, for example, is often discussed in this discourse as having implications for other ethical considerations like agency, responsibility, etc. To demonstrate this relationship, Klein et al. provide a series of questions that a typical DBS user might consider. Each question alludes to a particular ethical concern, but it is difficult to contemplate potential responses without also thinking about one’s sense of identity.

> “If a device is stimulating my brain while I decide upon an action, am I still the author of the action? Should I be held accountable for every action in which a device is operative? Does a device make the interiority of my experience accessible to others? Will the device change the way I think of myself and others think of me?”
>
> (Klein et al., 2015)

We are deeply driven by our sense of identity. It is a condition of autonomy (Levy, 2007), agency (Haste, 2004), and responsibility (Glannon, 1998). Identity influences what we are motivated to do, how we perceive ourselves and others, and our interactions with our environments (Oyserman et al., 2012). The feeling of knowing oneself is an important mental processing tool and a source of wellbeing. Therefore, it is likely that a stable, integrated identity will result in a healthier, more mature individual (Buckingham, 2008).

The value of being oneself lies in its authenticity. We strive to live a life that is authentic to us, where we can act according to our own values and beliefs to achieve our own goals. In order to be authentic to our sense of identity, we desire for our way of life and values to come from within (Levy, 2007). For this reason, even the slightest changes in identity can have significant implications for emotions, behaviors, etc. This highlights why identity is an important consideration in ethics, and why manipulations of the brain, such as through medications and neurotechnology, pose significant concerns about whether one can remain authentic to oneself in the midst of such externally derived influences.

> “It would be worrying if Prozac altered my personality, even if it gave me a better personality, simply because it isn’t *my* personality. This kind of personality change seems to defy an ethics of authenticity.”
>
> (Elliot, 1998)

Deep brain stimulation vs. medication

Even if one does accept Elliot’s claim that inauthentic identity changes as a result of medications are unethical, it should be said that even when we know of the potential concerns and risks, we are still mostly accepting of the use of medication for a number of illnesses. We could argue then, that we ought to accept the widespread use of neurotechnologies like we do with pharmaceuticals. By the same reasoning, it could be argued that medication and neurotechnology should be held to the same standard of ethics, and that there is no further issue with the use of DBS.

There *is* some hesitation with this statement though, because it does not seem as though deep brain stimulation is as un-concerning as medication; I would not so easily sign up for DBS as I would sign for my prescription medications. Apart from my simply being familiar with the use of medications, there must be some defining feature(s) about DBS that brings discussions of its use to the forefront of ethics discourse.

First, DBS has a different mechanism of action that medications. One can think of DBS as being a precise, potentially direct application. Pharmaceuticals target specific chemical receptors, which may not only be present in the brain, but also in different organs of the body. Hence, medications taken over extended periods of time can have adverse side effects to the body. Electrodes, on the other hand, are implanted in precise target areas of the brain, though this poses another set of risks. As DBS is less researched than many common medications, there exists another set of risks associated with the uncertainties related to ideal target areas or stimulation frequency (Glannon, 2008). . There is, however, an uncertainty surrounding the use of DBS that is not entirely present with pharmaceuticals (Glannon, 2008). Such uncertainties for an application that requires precision can unwittingly bring about unintended outcomes and side-effects.

Second, deep brain stimulation involves extremely invasive surgical procedures to implant 1) electrodes into the deep structures of the brain via holes drilled into the skull and 2) a battery, designed to power stimulation, under the skin of the chest. The operation is considered high-risk, with the potential for complications from surgery, such as brain hemorrhage, and infections at the surgery sites (Weaver et al., 2009). Further, additional surgeries will be required to replace batteries, which last for approximately 5 to 10 years depending on the type of battery and use of stimulation. Due to the seriousness of these risks, there are strict eligibility criteria for pursuing DBS (Munhoz et al., 2016). Primarily patients who are either unable to take medications or are resistant to other treatments are advised to consider DBS.

Third, there are greater obligations required of patients. DBS is a more specialized form of therapy, requiring a particular skill-set that not all providers are equipped with, while those who do specialize in deep brain stimulation therapy are not always easily accessible to patients. If this is the case, there might be extended travel time to visit providers or, particularly for uses of DBS in research, patients might be required to move in order to be closer to their provider and the study. Although deep brain stimulation can significantly reduce symptoms, it is not a cure for any disease or disorder. Therefore, the device must continually apply stimulation in order to receive clinical benefits from it. Unless there are complications requiring explantation of the device, DBS is intended to be a long-term intervention requiring extended commitments from the patient.

Lastly, deep brain stimulation is expensive. Initial costs include the device itself and the surgical procedure for implantation, while long-term costs must cover those for device management, such as physician’s visits and battery replacements. While approved uses of DBS are covered by most insurance providers, it is estimated that the total cost of DBS for Parkinson’s patients is approximately $170,000 for three years, although this number partially depends on the target site (Stroupe et al., 2014). It should also be noted that for most uses, DBS is not an independent therapy. That is, most patients remain on medication while also undergoing stimulation and, therefore, are responsible for both costs.

The complexity involved in deep brain stimulation, compounded by it higher-risk nature, is a source of greater concern when compared to more traditional pharmaceutical therapies. As a result, it is particularly important to consider the potential positive and negative outcomes that may occur as a result of DBS.

Early perspectives: the case of the Dutch patient

In some cases, shifts in identity can be considered a positive development, even if it was unintended. As persons, we continually strive to develop our identities in ways that are in line with the goals that we have for ourselves. So, we might welcome changes as being more positive if we perceived them as having brought us closer to our desired self or put us in a better position. However, if interventions like DBS alter or interrupt this process of identity development, they might be considered disruptive to the self, especially if they caused more negatively perceived or undesired outcomes. In these instances, device-based alterations can undermine identity in a way that comes as a cost to users, leading to questions about the preservation of identity during DBS (Klein et al., 2015). At the forefront of these discussion are reports that patients who had undergone DBS for Parkinson’s disease “experienced difficulties in their relations with themselves, their spouses, their families, and their socio-professional environment” after surgery, stemming from a sense of “dislocated self… a distressed mind in a repaired body” (Schüpach et al., 2006).

One case study often included in ethics literature as an example of the unintended personality-changing side-effects of DBS is presented by Leentjens et al. (Leentjens et al., 2004). The authors illustrate the case of a 62-year-old male who received DBS for advanced Parkinson’s and became impulsive, manic, and eventually declared mentally incompetent. Upon adjustment of the stimulation the patient’s mania subsided and his cognitive capacity for rational judgment was restored, although it ultimately resulted in the return of motor symptoms so severe that he became bedridden. The result of the case became a topic of identity versus autonomy – the right to make informed, uncoerced decisions. When the stimulation was on, the changes were so severe that the patient was no longer determined to be himself by his caretakers and providers. When the stimulation was off, however, the patient was considered to have returned to himself, at which point he was permitted to decide to leave the stimulator on in exchange for his stay in a psychiatric hospital (Glannon, 2009; Kraemer, 2013).

This case is presented here as an extreme, but it is these types of early perspectives that cause worry about the potential changes that DBS can cause to identity. Namely, that it affects behavior in such a way that it is incongruent with patients' perceived self. If they are no longer considered to be themselves, then they are incapable of acting authentically in ways to bring about their goals. Given that we place value on authenticity in identity, cases such as these illustrate the relationship between identity and deep brain stimulation.

Personality changes

Commentary on the ethics of DBS have often included potential changes to identity in their analyses (Baylis, 2013; Glannon, 2009; Goering et al., 2017; Klaming & Haselager, 2013; Klein et al., 2015; Müller & Christen, 2011; Schermer, 2011), while Klein et al. have found it to be a primary consideration for patients using the intervention in empirical studies (Klein et al., 2016).

Discussions on the ethics of DBS often include potential issues to identity. However, as I have explained identity in the previous sections, it is difficult to characterize what identity refers to in practical applications. Personality, that is, the distinctive qualities or characteristics that make up an individual, has similar features to identity. In particular, cognition, mood, and behavior are elements closely associated with personality (Johansson et al., 2011). Consequently, the two terms are often used synonymously when referring to empirical investigations of identity in DBS (de Haan et al., 2017, Goering et al., 2017, Johansson et al., 2011).

Unintended changes to personality is a concern when discussing the ethics of DBS. As shown in the case study, such changes to personality, mood, and behavior raise significant concerns about stimulation's potential effects on patients' sense of identity. As shown by the case study, changes in personality and mood are indicative of stimulation's effects on identity. Many patients who have received stimulation for Parkinson's disease experience symptoms of hypomania and/or impulsivity, likely as a result of the stimulation sites (Cyron, 2016; Frank et al., 2007). However, irrespective of stimulation sites, such alterations to personality, mood, or cognitive abilities as a result of DBS that undermine the "unity and continuity of the psychological properties that make each of us a unique person" would, therefore, represent a threat to identity if they were incongruent with the properties that a healthy individual would persistently endorse over time (Glannon, 2014).

Alienation from oneself

If patients perceive changes in their identities to be directly caused by stimulation rather than by authentic wills of the self, then DBS could potentially result in feelings of alienation. That is, the device risks causing patients to feel unlike themselves or strange in their own bodies. Schüpbach and colleagues' seminal work on outcomes of DBS for Parkinson's collected testimonials from patients who reported "a feeling of strangeness and unfamiliarity with themselves after surgery ('I don't feel like myself anymore,' 'I haven't found myself again after the operation')" (Schüpbach et al., 2006). In some declarations, patients note feeling entirely detached: “I feel like an electric doll” (Schüpbach et al., 2006), while others noted feeling “like a robot” (Mecacci & Haselager, 2014).

While these outcomes may be alarming to some (Witt et al., 2003), others do not seem to share this apprehension, noting an overuse of the same sets of evidence and quotes that perpetuate hype without producing enough empirical value (Gilbert et al., 2018). In fact, Gilbert et al. argued against the overuse of such data, arguing that the quote by Schüpbach et al. was inaccurately translated and instead should have been “I am an electric doll” (Gilbert et al., 2018). They claimed that “words such as ‘I feel’ or ‘I am’ largely differ in their meaning” and “does not represent robust evidence” (Gilbert et al., 2018). Despite accepting that feelings of alienation do constitute a potential concern in deep brain stimulation, alienation is not only a symptom of neurotechnologies like DBS, but also of the illnesses they treat:

> “Alienation can also be cured by DBS as other patients experience their state of mind as authentic under treatment and retrospectively regard their former lives without stimulation as alienated.”
>
> (Kraemer, 2011)

Mecacci and Haselager consider these types of complications to be “maladaptions” of the implantation of DBS, implicating the devices for their negative effects (Mecacci & Haselager, 2014). Other researchers have granted the likelihood that while DBS might have a direct impact to modes of thinking and identity, it does not exist in a bubble. In Parkinson’s disease, the most common illness treated by DBS, positive changes in mood or personality can be attributed to reduced stress and depression with the improvement of the motor symptoms, while it has also been reported that negative responses like periods of lower mood and higher anxiety may be less related to identity changes and more as an indirect result of poor adjustment and reintegration into social and professional environments (Agid et al., 2006; Schupbach et al., 2006). As such, social implications can impact treatment outcomes, although, as will be discussed later, social interaction and integration is, in a sense, a feature of identity.

Identification with the device

The broader concern with neurotechnologies like DBS relates to whether or not the user can, or should, integrate the device into his or her self-identity (Klein et al., 2015). Because an issue with DBS is the feeling of alienation from oneself as a result of the device's control over brain states, a resolution would be to integrate the device into one's self-image; to see the device as a part of one's identity would no longer distinguish it as an external influence.

Francois Baylis, for example, takes issue with the claim that DBS is a threat to identity, despite the "profound changes in behavior, mood and cognition (characteristics closely linked to personality)" (Baylis, 2013). Identity is formed by the integration of one's experiences into a single narrative, intended to be continually shaped and reshaped over time. Her argument states that by recognizing identity as fluid, experiences created by DBS, regardless of whether or not its effects are biographically disruptive, remain "constitutive of personal identity" and, as such, "do not represent a threat to personal identity" (Baylis, 2013).

The foundation of Baylis' theory of identity follows a similar construction as many others, which tend to acknowledge a narrative or autobiographical aspect to identity. Narrative is a key feature for maintaining a continuous psychological state over time. Identity is "forged in the social sphere located within temporal relations… The inter-relationship between past, present, and future in the on-going work of developing an identity suggests that who we are, what we do and what we become changes over the life course" (Kehily, 2009). Such articulations imply a fluid, dynamic nature to identity that Baylis bases her argument. Her point is that identity must be negotiated according to new experiences, so as one experiences changes that occur as a result from stimulation, all one needs to do is reflect and renegotiate his or her identity. By this reasoning, DBS would not be more threatening than any other life event like marriage, job loss, the birth of a child, a car accident, etc. These changes can permanently alter the narrative of life, but they are non-issues because the fundamental concept of identity cannot be threatened, only changed.

However, Baylis' argument seems somewhat inadequate. Despite the narrative aspect of identity, it is easier said than done to resolve the effects of DBS as the same as having been produced by one's authentic self. Here, issues in identification still exist, particularly if one views the changes as being unexpected or of inorganic origin, and "can disrupt the normal, 'narrative flow of life' and it may take time and effort of the patient to pick up and continue his life story" (Schechtman, 2010). Sara Goering echoes this sentiment, claiming that "identity as fluid" does not adequately respond to the innate concern about DBS, whose potential risks can still negatively affect one's identity if it is envisioned as being a disruptive or controlling influence: "telling me that the DBS is now part of the big system that is me won't mean that the rest of me easily acquiesces to its influences (or should)" (Goering, 2014). There still seems to be a problem if the DBS itself causes changes to your identity that you do not endorse or desire. You would avoid things that don't help you acquire your goals, or the future mental states and identities you want. If you knew or were worried about DBS changing you in ways that you do not want for yourself, it would not be incorrect to consider DBS a potential threat to your identity such that you would have serious reason to weigh the benefits to the risks (Goering et al., 2017).

Agency and authenticity

Baylis claims that DBS is not a threat to our identities insofar as it allows for the narrative identity to continue, where individuals are able to interpret and adapt to their experiences. She does note, however, that is a threat *only* as it undermines agency "to such an extent that the person is no longer able to meaningfully contribute to the authoring of her own life (i.e., to contribute to the cyclical and iterative process of projecting, defending and revising a self-narrative)" (Baylis, 2013). Identity serves as the basis for motivation and influences action. Without the ability to contribute to the process of identity formation, a person cannot maintain ownership over those things that identities value and, as a result, are unable to hold on to a sense of self. If this is the case, then these disruptions in psychological continuity can also have an effect on mental competency, considered the ability to interpret relevant information and make an informed decision based on knowledge of the information and how it might relate to one's goals and desires (Klaming & Haselager, 2013). Here, the issue of DBS is less about whether outcomes of stimulation or any resulting effects on personality, mood, or behavior are considered to be desired or undesired. The morally significant feature is that these effects would not be as a result of authentic origin by an actor. Rather, DBS would be a threat to identity if it were to undermine the patient's sense of agency, and thus, autonomy.

While Baylis' argument raises an important concern regarding deep brain stimulation's impact on identity, it is less likely that alterations in behaviors and thoughts will occur in manners that separate persons from their sense of self entirely. However, it does illustrate the basis of researchers' concerns that DBS, whose external influence might liken it as third-party actor, introduces uncertainties over authorship of actions (Wegner, 2003) or sense of agency (Gallagher, 2000). Behaviors or thoughts that are noticeable as being "unlike someone" might suggest that such acts are not derived from the person, but from the device. Actors may be insecure about whether the resulting actions performed were genuinely their own, derived from their own authentic motivations. Even if they had behaved in a way that brought about outcomes that they desired, they might wonder if they had done it or not and question if they were responsible for said outcomes. This also holds greater implications for responsibility, where uncertainty regarding if an actor was responsible for their actions questions how much we ought to hold them morally or legally accountable for their outcomes (Haselager, 2013).

Ethical considerations of DBS for depression

Due to the versatility and effectiveness of deep brain stimulation, further encouraged by its success as a therapy for Parkinson's disease, its application has been extended to include psychiatric disorders (Anderson et al., 2012). One such use is for individuals with intractable major depression. Early studies have highlighted the potential for positive outcomes (Lozano et al., 2008; Mayberg et al., 2005; Schlaepfer et al., 2007). Yet, DBS for depression remains an experimental treatment, as later trials that were considered unsuccessful for failing to meet the primary outcome goal, brought up questions about its therapeutic value (Cavuoto, 2013; Dougherty et al., 2015). There are clear clinical benefits if DBS is successful, such as reduced severity of depressive symptoms and improved quality of life. However, the invasive nature, complexities of maintaining the intervention, and uncertainties surrounding the mechanisms of deep brain stimulation, compounded with a lack of understanding about the biological basis of depression, have raised concerns over the ethical use of DBS for depression.

The ethics discussions regarding DBS and identity also apply when discussing the use of DBS for TRD, but the primary distinction between the two dialogues has to do with how depression impacts those who are diagnosed with the disorder. The addition of depression shifts how we approach our examination of ethical practices and risk-benefit analyses. Depression is a disorder that significantly affects mood and cognitive function. As such, the application of deep brain stimulation as a potential therapy for depression, as it pertains to the concept of self, must consider the relationship between identity, depression, and DBS. Like with DBS generally, does the use of DBS specifically for depression still risk undermining identity, or does it assist in unveiling identity from the cover of depression (Klein et al., 2016; Kraemer, 2013)?

Due to the small number of empirical studies that have been conducted to investigate the therapeutic potential of deep brain stimulation for depression, little is known about the outcomes of stimulation for mediating depressive symptoms or the additional risks that may arise as different targets in the brain are studied (Appleby et al., 2007). As such, one more relevant ethical concern at this stage of DBS for depression is whether depressed patients are autonomous agents. That is, they have capacity to make informed decisions, particularly as it relates to the choice to pursue deep brain stimulation.

In order to understand how depression might shift the discussion of identity, we must first understand why mental competency and decision-making capacity are important to identity, and how depression impacts competency. Let me briefly explain these connections before we return to our discussion on identity itself.

The principle of autonomy, in its simplest sense, "encompasses self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding" (Beauchamp & Childress, 2013). Immanuel Kant developed the notion that autonomy grants the respect of persons as ends in themselves, justifying the right to having authority over oneself to act in pursuit of one's own happiness (Timmons, 2013). In this respect, identity has a dual role in autonomy. In one sense, autonomy is the right to act in ways that both develop and preserve one's concept of identity or desired self. In the other sense, one needs an existing sense of self in order to truly exercise autonomy and ensure that he or she is acting in his or her own interests.

Respect for autonomy is also a fundamental principle in medicine, where autonomous choice is protected by the requirements of informed consent. Beauchamp and Childress describe a set of conditions required for informed consent:

> (1) The physician or treating team discloses to the patient all medically relevant information about a diagnosis and prognosis of the patient's disease, the proposed therapy to treat it, the potential benefits and risks of the therapy, and alternative therapies.
>
> (2) The patient has the mental capacity to understand his or her condition and the medical information presented to him or her.
>
> (3) The patient is not coerced or compelled, but autonomously decides to have or forgo the proposed treatment on the basis of this information. For an intervention in the brain such as DBS, the patient must have the capacity to weigh the potential benefit against the potential harm in deciding whether or not to have it.
>
> (Beauchamp & Childress, 2013)

Condition (2) states that patients are required to have the mental capacity to make informed decisions. According to Beauchamp and Childress, patients are considered competent "if they have the capacity to understand the material information, to make a judgment about this information in light of their values, to intend a certain outcome, and to communicate freely their wishes to caregivers or investigators" (Beauchamp & Childress, 2013). If it were determined that depressed patients lacked mental competency or capacity, then by allowing such persons to become involved with interventions like deep brain stimulation, which could harm them, we would be failing to uphold the ethical standard of care. In order to promote DBS to be approved as an established therapy for depression, like it is for Parkinson's disease, it will be necessary for more research to be done to gain a more conclusive result about its effectiveness for mitigating the clinical symptoms of depression and achieving wellness. Therefore, to move research forward it will be necessary to gain a clearer understanding about the ethical nuances surrounding DBS for depression.

Depression's influence on mood, perception, and cognitive functions can potentially result in changes to one's values, preferences, and goals such that it risks undermining one's sense of identity and, as a result, the capacity to act autonomously (DeGrazia, 1994). Further, there is concern about if and how treatment resistant depression might produce feelings of desperation or anxiety in patients' who might consider experimental DBS a last resort (Dunn et al., 2011; Miller & Fins, 2006). However, this does not necessarily indicate that depressed persons are unable to understand procedures or adequately weigh the risks versus benefits and make a reasonably informed decision regarding DBS (Elliot, 2006; Glannon, 2008; Kim, 2004). Grisso and Appelbaum showed that only 5.4% and 7.6% of inpatients with depression displayed impairment in understanding and reasoning, respectively (Grisso and Appelbaum, 1995). With regard to consent processes, Fisher et al. found that severely depressed patients did not present with impairments and produced "accurate appraisals of the trials' risks and benefits, were able to distinguish among a variety of procedural risks, and expressed reasonable hopes for personal benefit" (Fisher et al., 2012). In fact, they found that patients who presented with higher clinical depression scores were able to more precisely evaluate the risks and benefits, producing less of a risk for therapeutic misconception (Fisher et al., 2012; Rudnick, 2002).

While empirical evidence found that depression did not significantly undermine decision-making capacity or affect the ability to rationalize decisions, the public are more likely to perceive those with mental illnesses as having decreased decisional capacity (Muroff et al., 2006). This discrepancy between attitudes on the decisional capacity of those with mental illness indicates that both promoting and protecting the autonomous decisions of patients should remain of utmost importance. Dunn et al. argue for more thorough informed consent practices (Dunn et al., 2011). They claim that while DBS for severe, intractable psychiatric illnesses like depression may still introduce additional worries to be aware of, evidence finding similar decision-making capabilities between patients with treatment resistant depression and other high burden chronic diseases (Grisso and Appelbaum, 1995; Lapid et al., 2003; Appelbaum et al., 1999) support the use of informed consent processes that are similar to those for other high-risk procedures (Dunn et al., 2011).

Ultimately, individuals with treatment resistant depression are capable of effectively analyzing the potential risks and benefits of DBS as it relates to their decision to pursue the experimental treatment. Regardless, this still does not discount the fact that depression is a debilitating illness capable of disrupting identity. If DBS is able to effectively manage depressive symptoms like anhedonia and decrease of energy, then, particularly in cases of depression, stimulation could serve to increase autonomy than threaten it (Beeker et al., 2017). Patients who have undergone DBS for their intractable depression have provided some evidence supporting this theory that stimulation increased autonomy and agency, by restoring their identities rather than threatening them (Klein et al., 2016; Patterson, 2014). Klein et al. asked patients using DBS for their depression what they considered to be important aspects of their experiences. They found that “patients reported that an attractive feature of DBS… is the opportunity to experience a more authentic self” (Klein et al., 2016). Patients considered their DBS to have either unveiled their identity from the cover of depression (“Go back to the more authentic you,” “I’m me without depression”) or allowed for them to regain control over their identities through the reduction of depressive symptoms (“I am aware of having feelings that I never knew existed before”) (Klein et al., 2016).

With regards to the latter perspective, another patient who received DBS for depression elaborates further on how her progress has allowed her reintegrate into her narrative identity and live a new life:

> "Mostly, I have a new sense of perspective… I get to build a new 'me.' I'm changing my behaviors, beliefs, thoughts, and feelings. I am creating a new life based on what I value, because my goal has never been to return to the life I had before. I get the opportunity to implement all the tools from therapy that I have learned, with the hope that they will help me be more effective. Now that I have my implant, life is all possibilities."
>
> (Patterson, 2014)

Deep brain stimulation has the potential to positively impact identity in patients with depression. However, empirical research on deep brain stimulation's clinical effectiveness is limited, and progress in this area may be hindered unless we can properly evaluate the ethical concerns that ground this research. The remainder of this work will address the ethics of DBS for depression, particularly as it affects identity. The goal of this project is to identify themes that provide insight into the identity changes that occur during DBS for depression.

This thesis will investigate how patients' experiences with DBS for their intractable depression affect notions of identity, and how these might influence decisions to become involved with this experimental therapy. This will be done by establishing themes related to identity that assist in providing insight into the relationship between identity, DBS, and depression.

Research design and methods

Research design

Early discussions on the ethics of deep brain stimulation prompted the assumption that manipulations of the brain produce changes in personality, behavior, etc. that negatively impact identity. While counterarguments have been made claiming that identity is not affected by DBS or depression at an amount that the risk outweighs the potential benefits, much of these discussions have been based on theory (Baylis, 2013; Fisher et al., 2012; Glannon, 2008). Empirical evidence on the subject is limited, partly due to the complex and controversial nature of DBS for depression, resulting in fewer research studies being conducted. Further, the perspectives of individuals who have personal experience with DBS for depression are often not included in discussions on the potential identity changes from stimulation. Gilbert et al. find that despite an increase in assessments of DBS-induced identity changes, there is a disproportionately limited amount of empirically-based evidence available to support these claims (Gilbert et al., 2018). As a result, rather than furthering ethics discussions in an effective and efficient manner, debates that utilize "very limited empirical evidence and is, instead, reliant on unsubstantiated speculative assumptions probably in lieu of robust evidence" only risk spreading misinformation and hampering the development of ethical practice (Gilbert. et al., 2017). Thus, there is an impetus for further empirical work in order to adequately characterize the effects that deep brain stimulation may have on concepts of identity, especially for individuals with treatment resistant depression.

The limited empirical evidence available has produced a gap in knowledge, where the concerns regarding identity in DBS for depression cannot be adequately responded to using empirical data and, as a result, reliably translated into practical applications. In this regard, patient perspectives can provide a valuable source of information in this investigation. Due to their direct involvement with deep brain stimulation for depression, they have a unique experience and knowledge set to provide perspectives on its outcomes measures. Their participation is imperative to guiding discussions on the ethical practice of DBS for depression. This project seeks to assist in furthering DBS for depression research by evaluating patient perspectives in conjunction with various theories of identity.

This project will not seek to create a complete risk-benefit analyses as it relates to all potential outcomes of DBS for depression. Instead, it will focus on one particular area of concern for bioethicists – identity – and attempt to provide a more complete account of patients' concepts of identity during their experiences with DBS for depression. The primary aim is to analyze patient perspectives in order to ascertain relevant themes of identity that might be indicative of how experiences with both DBS and depression affect features of identity. These themes will ultimately assist in providing the necessary context to better consider and respond to the ethical considerations of DBS for depression, particularly as they might apply to risk-benefit analyses.

Methods

A qualitative pilot study was conducted to investigate perceptions of identity in individuals who have undergone deep brain stimulation for treatment resistant depression. Methods included analysis of video transcriptions of participant interviews taken during the course of an ongoing study at Emory University investigating the clinical effectiveness of deep brain stimulation for treatment resistant depression.

The perspectives collected for this project were from patients involved in the study. The purpose of the ongoing study at Emory is to explore the effectiveness of applying electrical stimulation to Brodmann area 25 (BA25) in mitigating the clinical symptoms of patients diagnosed with treatment resistant depression. The primary researchers at the site consist of psychiatrists responsible for monitoring the study participants – who have all agreed to receive stimulation for the purposes of the study – and collecting data on the perceived effectiveness of DBS. Their responsibilities include conducting regularly scheduled appointments to follow up on the participants' clinical progress with DBS and to, based on their professional judgements on best routes of care, manage and adjust the device stimulation accordingly.

The data provided for this research project consisted of video recordings taken from these appointments. The videos were formatted as psychiatric interviews, where researchers ask the participants open-ended about their symptoms and progress, as well as personal experiences with depression and the DBS. Because of the long-term nature of the research study, which provides DBS to its participants indefinitely, there is documented data spanning several years. This provided a valuable source of information for my analyses, as it provides a complete account of differing experiences and perspectives as participants progress through deep brain stimulation for treatment resistant depression.

The sample size of this project was five patients. Background on the patients is shown in Table 2. Video interviews and partial transcripts for certain sets of videos were provided for each patient. The number of videos per patient and the points at which each video was taken was selected at random. However, each subject had video interviews spanning at least two years. Table 3 provides a complete account of the video interviews that were used in this project. Videos were organized in 4 phases: (A) pre-implantation, (B) post-implantation, stimulation off, (C) stimulation on, (E) long-term follow-up period with stimulation turned on (≥ 6 months). Videos in which stimulation was turned off provided information on patient expectations and goals, while those where stimulation was on detailed patient experiences with the DBS.

Patient	**A**	**B**	**C**	**D**	**E**
Gender	F	F	M	F	M
Age (years)	48	48	63	57	55

Table 2. Patient demographics

Accompanied with the video references in Table 3 are patients' depression ratings patients taken during the same visit as when the videos were recorded. The project site made use of the Hamilton Depression Rating Scale (HDRS), among other forms of assessments, to clinically assess the severity of patients' depression at the time of the interviews. These depression scores allow researchers to gauge patient progress and evaluate the clinical effectiveness of the DBS in mitigating patients' intractable depression. Knowing the level of depression severity also helps put patient perspectives in context as they detail their experiences with DBS and depression. This will be particularly helpful in my analysis.

In general, trends show at least some reduction in severity of depression. Hamilton score trends in patients A, C, and D suggest a greater and more consistent reduction in severity of depressive symptoms, though I grant that the presentation of depression scores in the table is incomplete. As such, the accuracy of trends in depression scores is potentially limited.

Transcriptions of patient-researcher interviews were created for more accurate data collection and analysis, which was done by identifying sections of the transcriptions that demonstrated relevance to identity. These sections were then categorized into defining codes, used to signify the primary subject matter present in a particular section. Repeating codes with significant meanings were then examined and organized into central themes based on their connections to one another. Both inductive and deductive a priori approaches were found to be beneficial processes of thematic analysis, whereby the a priori approach allowed for the previous literature review to inform data analysis while the inductive approach allowed for additional potential themes to emerge out of the data itself (Fereday & Muir-Cochrane, 2006). The literature review of identity provided in previous sections was used to build a working definition of identity prior to data analysis. The video interviews were not created for the same purposes as this project. As a result, having a pre-established understanding of identity prior to analysis allowed me to gain insight into potentially relevant characterizations of identity present in the conversations between patients and researchers in the videos. Thematic analysis was done using the ATLAS.ti coding software.

Based on their experiences with DBS for depression, these participants can provide valuable insights that can respond to theories on the effects of DBS and depression on personal identity. In order to better inform data collection processes from the transcripts, an analysis of the existing literature on different theories of identity was conducted. This information, used to deductively collect potentially relevant data, provided a clearer working understanding of identity as it might be affected by depression or deep brain stimulation. The section that follows provides an overview of some existing theories and features of identity as they were used to guide data collection and analysis for this project.

Video/Transcription (Phase-Week) * | HAM-D **	Pt. A		Pt. B		Pt. C		Pt. D		Pt. E	
	A-1	21	B-1	13	A-2	20	C-13	15	C-2	9
	A-2	24	B-4	17	A-4	22	C-14	12	C-3	11
	A-3	20	C-2	11	C-4	15	C-15	14	C-4	11
	A-5	24	C-3	11	C-5	10	C-16	8	C-6	13
	C-6	2	C-4	10	C-6	11	C-17	8	C-9	6
	C-8	5	C-6	11	C-7	12	C-18	7	C-11	4
	C-9	12	C-7	14	C-8	7	C-21	9	C-12	7
	C-10	11	C-9	15	C-10	7	C-22	5	C-13	4
	C-11	3	C-10	23	C-11	9	C-24	7	C-14	9
	C-13	4	C-13	10	C-12	11	E-4	6	C-16	5
	C-14	22	C-14	12	C-14	11	E-36	8	C-18	18
	C-15	9	C-15	9	C-15	7			C-19	6
	C-18	9	C-16	12	C-17	7			C-21	13
	C-24	3	C-17	8	E-65	7			C-25	6
	E-11	6	C-18	9					C-26	10
	E-25	3	C-19	10					E-16	2
	E-127	4	C-20	16						
	E-179	2	C-21	16						
			C-22	11						
			C-23	7						
			C-24	8						
			C-26	7						
			C-28	6						
			E-24	14						
			E-40	7						

Table 3. Videos/transcriptions of interviews that were used for analysis

* Phase-week formats are used to indicate the point during the study at which the interview occurred, where the weeks start at the beginning of each phase. The phases are as follows: (A) pre-implantation, (B) post-implantation, stimulation off, (C) stimulation on, (E) long-term follow-up period with stimulation turned on (≥ 6 months). For example, C-12 would indicate that the interview occurred 12 weeks after the stimulation was turned on.

** Hamilton Depression Rating Scale (HAM-D) was one scale of measure used to determine severity of depression during visits. Numerical scores correspond to depression severity, where higher scores indicate greater severity: normal (0-7), mild depression (8-13), moderate depression (14-18), severe depression (19-22), very severe depression (≥ 23)

Themes

Analysis of the patient interviews revealed five themes that shaped how patients interpreted their experiences with deep brain stimulation for their treatment resistant depression as impacting their sense of identity. These themes are: well/unwell distinctions, control, narrative, relationship with others, and changes in perception. Table 4 provides an overview of these themes and their sample codes.

Essential themes of identity in DBS for depression	
Theme	**Sample Codes**
Well-unwell distinction	*normal; functioning; 'old self'; 'used to be'*
Control	*causation; guilt; self-determination; responsibility; futility*
Narrative	*past self vs. present self, narrative, perception of self, identification, reorienting*
Relationship with others	*"other"; alienation; connection; social roles; negotiation*
Changes in perception	*permanence; futility; hope/hopeless; reality; rationality*

Table 4. Overview of essential themes and a sampling of their associated codes

Well-unwell distinction

Distinctions between well and unwell quickly emerged as a relevant theme from the interviews. Codes related to this distinction presented as a means of comparison between depressed and non-depressed states in parallel to present self and past self. Indications of "normal" became relevant codes once it was apparent that patients measured their progress by a function of normality, where wellness was associated with statements of normalcy.

> *"I was having a range of emotions and it felt normal. And any dip in my mood felt like it was related to something, like a sadness or loss or something environmental." (Pt. A; C-6)*

> *"I'm not sure what it is, but I'm not real able to put words to what I- what I feel. Only that it's okay. And maybe this is normal." (Pt. A; E-11)*

> *"When I wake up mornings now and I'm feeling depressed, I know it's not going to last long. So, it's not as bad. I mean, even waking up this morning. I mean, I woke up feeling not sad, you know. I can't say I woke up feeling normal. I woke up and I wasn't sad." (Pt. E; C-11)*

In this set of quotes, patients often measured their progress using a function of normality. It seemed that interpretations of increased wellbeing, congruent with a reduction of depressive symptoms, were associated with feelings of normalcy. As such, in associating better states of wellness what is normal, it would be the case that declarations of feeling normal were associated with states where they considered themselves to be closest to depression-free.

> *"Right now. I feel like I have a pretty normal existence and depression is not a part of it." (Pt. A; E-127)*

> *"It was almost like normal." (Pt. E; C-25)*

Patients further distinguished depressed states from those of wellness according to what they considered to be the standard experiences of others.

> *"The kind of suffering that's out there is sadness and grief and loss and those kinds of things that are normal. And the suffering that's back in the [depressed state] is not normal." (Pt. D; C-18)*

> *"I don't know what normal is. I don't know what for other human beings not being depressed feels like." (Pt. A; C-8)*

> *"I'm trying to get out of this [depression] and um, you know, get the most out of it, and get back to normal. Or as normal as normal can be. I don't know what that's going to be." (Pt. E; C-4)*

Indicating that others' normalcy is contingent on the sole condition that they are not depressed is to place a value judgement on the condition of being not depressed. Of course, to be not depressed is a reasonable desire, but it calls into question what it means to be not depressed, and further, what it means to be well.

Patients' perceptions of wellness while they were in depressed state were indicated by comparisons between present selves with past selves. When asked by researchers to elaborate on their experiences and goals for stimulation, many patients anchored their normality responses to their past identities.

> *"I was actually feeling so like my old self… I was back to normal again in every way." (Pt. C; C-12)*

> *"Participating directly in a conversation is not something that I would do. Not like I had when I was well, you know, years ago when I wasn't depressed." (Pt. B; C-6)*

This suggests that patients' references to what is considered "normal" are rooted in their past selves rather than an objective norm, although it still recognizes that past states held value. In this sense, assumptions about well versus unwell states were subjective to the patients' perception of what it meant to be well or in their ideal states based on previous experience. As such, wellness could be achieved once states that resembled past ones were reached, such as in statements like "I feel like the old me." Therefore, when asked what they were expecting or hoping to gain from DBS, some patients would reference past states, as if the "old self" that was less impacted by depression was the self that was the better state to be in.

> *"I want to live for [life] and enjoy again because I always did. I loved life and before this specter happened to me, um, I just really want that back." (Pt. C; C-4)*

> *"I would want to do things that I used to do." (Pt. B; E-40)*

Depression was characterized as entirely separate from states of wellness, as if the two were exclusively separate from one another. Depression was associated with abnormal such that patients could only consider themselves to be normal if they had separated themselves from depression.

> *"Right now. I feel like I have a pretty normal existence and depression is not a part of it." (Pt. A; E-127)*

The fact that patients viewed their past states as ones of value alludes to their thoughts about how their view themselves in their depressed states. According to the personal sense of identity, we are likely to associate ourselves with characteristics that we find to be a source of dignity in. It seems that in idealizing pasts states as more valuable, patients, in a sense, reject their current states as being part of their identities, potentially viewing depression as a facet of their shift away from their ideal selves.

Distinctions between well and unwell states were associated with the presence of depression, where patients assumed that the absence of depression would necessitate wellness rather than the presence of other qualities or behaviors related to wellness. Further, comparisons of past to present selves could be used as a tool to measure progress. Patients considered depressive states to be abnormal, while past states of wellness that were either less impacted by depression or were depression free were normal. Here, DBS could be seen as a potential mediator between unwell and well states.

Control

Sample codes: causation; guilt; self-determination; responsibility; futility

Review of the identity theory literature illustrated implications for autonomy and agency. This theme of control refers to the condition of having agency such that the bases of feeling or self-determined action seem representative of one’s identity or self-concept. Discussions related to the origins of mental states or actions all seemed to indicate concern over the broader notion of control over the self. Patient interpretations of control differed significantly between experiences with depression and experiences with DBS.

The potential benefit of DBS is understood in terms of its effect on the clinical symptoms of depression. A majority of patients discussed symptoms related to mood as being a central tenant of their depression, although one patient considered physical activity to be an indicator of depression severity. They all noted being unable to attribute the presentation of severe depressive symptoms as being brought about by any particular events, or as a result of their doing.

> *"There is a sadness, but not connected to anything…" (Pt. A; A-1)*

> *"I just feel like I would feel if someone was- I got a call saying someone was, had died. And you're just so consumed with the fact that this person. You have to get used to the idea that you're never going to see this person again. And you just can't focus on anything else. You can't imagine getting out to do anything because you're so overwhelmed with sorrow from knowing that this person that you're so close is not there anymore, if that helps. But I don't know what I'm mourning." (Pt. B; C-10)*

> *"[on depression] it's beyond mood, it's beyond your control because it's a- your whole system is depressed." (Pt. B; B-1)*

Several patients identified the spontaneous appearance of symptoms as being a feature of their depression. With regards to identity, perhaps this inability to find causation within such emotions prompts a sense of missing control over the self. This lack of ownership over emotional states, which were often incapacitating, led to an expression of futility in all patients. In response to these depressed moods, patients voiced frustration at not being able to effectively manage their symptoms. Despite knowing how they ought to feel and wanting to respond in ways that would alleviate their symptoms, it seemed as though they were somehow unable to initiate such changes to their emotional and mental states, suggesting a sort of disconnect to being an agent who is capable of coordinating actions with desired wills.

> *"I don't know why I wouldn't will it all back if I could. But I feel like I should be able to adjust. Just do it. Just engage. Just snap out of it. It's not doing me any good hanging*

out down here in this pit. But I don't have any desire to climb out either. I'm just kind of trapped." (Pt. A; A-1)

"I couldn't force myself to do anything. Um, yeah. I really couldn't force myself to do anything." (Pt. E; C-12)

"That's the best way to put it. It's completely, completely out of my control. What I think, do, or therapy, or whatever has absolutely nothing to do with it. That comes when it wants to come and it goes when it wants to go. Period." (Pt. C; E-65)

Agency is an important feature of identity. There is a source of pride or dignity to acting in ways that are justified by your sense of personal identity. Therefore, conflicts in agency can perpetuate feelings of blameworthiness. Many patients spoke of a sense of futility and desperation, fueled by the guilt of being responsible for a state that only appears to belong to them, but that they cannot control.

"I feel guilty for all of that. I should feel better. Because otherwise I'm just taking up space." (Pt. A; C-9)

"I've had a tendency to blame myself for the depression and get caught up in how much of the depression could I have thought myself out of and why couldn't I think myself out of it before." (Pt. A; C-11)

> *"I still feel rotten, guilt, shame, discouraged… 'I'm not working hard enough. If I'm not putting enough into this.' The shame comes with, you know, with not wanting to see people. Not just because of the way that I am." (Pt. D; C-14)*

Deep brain stimulation changes the neuronal activity in the brain, resulting in changes to function. These changes alter the expression of depressive symptoms, as well as features of personality, manifested in mood or behavior. Such changes, positive or negative, were recognized by the patients, although, like with depression, they did not consider their states to have originated from their own conscious authority and were hesitant to trust that any positive changes were a sign of recovery. Patients often deduced the DBS was the primary cause of changes, although they were not always sure in what way.

> *"I don't know whether or not this device is doing something that's making, uh, something that hasn't- something that used to be there that hasn't been come back. I don't know." (Pt. C; C-4)*

> *"I guess there's the matter of how much I believe that something not in my complete control has made a difference. You know, I vacillate about whether I could make this happen on my own and whether I'm placebo-ing it, um, and that's been the case even when I was feeling depressed, wrestling with how much I'm responsible for the state of my mood." (Pt. A; C-6)*

> *"It doesn't seem like it was a decision I made. It just seems like my body is- there's some change in my body, like, physiological that's happening. Something that, like, may be neurological or something that may not be tied into decision-making and that's kind of*

separate from my own, um, decision to move, to tell my body to do something. And it responding better than it has been in the past. It doesn't seem like I've said, 'Okay. I'm going to put forth more effort and then get more response from it.' It's just like my body kind of gave me an allowance, so to speak, to be able to do what I wanted to do despite feeling bad." (Pt. B; C-22)

"Pt. D: That's actually a good way of saying that the DBS made a difference.

Pt. D's PARTNER: Oh, I mean I have no question the DBS made a difference.

Pt. D: Yeah.

Pt. D's PARTNER: I mean, otherwise it's just some giant, ridiculous coincidence that after two years of no response to any treatment whatsoever, all of a sudden you got well. That doesn't make sense." (Pt. D; C-21)

As noted with the experience of depression alone, this confusion over the causation of sudden symptom changes is a likely indication that these patients still did not directly cause them and, thus, lack the full control of an agent. However, unlike in their experiences with depression, many of these changes were considered to be positive and a step towards their idealized self. As a result, none displayed significant distress over this apparent absence of authority over their mental states.

"Sometimes I think 'I don't know if the DBS is on or if it's off, but I don't care because I feel good.'" (Pt. A; E-25)

> *"I don't know how to explain it, but I'm just like 'oh, I don't feel as depressed as I was. What have I done? I haven't done anything.' So that gives me encouragement." (Pt. D; C-22)*

> *"I guess I just have to go with what's happening and be glad that something is happening." (Pt. B; C-7)*

In fact, many agreed that the presence of DBS, and the changes to the depressive symptoms that it caused, put patients in a position to then behave in manners consistent with their identities. They felt as though they were able to better manage their depression in ways that would promote their wellness and that they were no longer prevented by their depression from acting in ways that they desired.

> *"I feel like I have better control over my depression than I did before." (Pt. E; E-16)*

> *"I'm okay with being responsible for how I behave in response to my emotions and my feelings, and it feels less out of my control than it used to. I don't know, maybe that's the DBS. I feel more capable of managing that 'thoughts and emotions' process." (Pt. A; C-13)*

> *"It's easier to get up. To literally get up and move…. When I command my body to get up and go do it, it's easier for me to respond. It's easier for me to initiate the movement and carry it through, whereas before it wouldn't be as easy because my body felt more heavy. But it doesn't feel quite as heavy." (Pt. B; B-1)*

> *"There is a component that I do feel I can control. And that's when I am feeling blah. I can go outside and do something different, get engaged, get myself motivated, eat well, and do all those things that I need to do to stay well." (Pt. A; C-6)*

> *"[DBS] puts you in position to at least try to do even the most normal things. You know don't wait for something to happen. Get up and see how you can perform a task and see what it feels like." (Pt. B; C-4)*

In this respect, in could be said that though both the depression and DBS caused state changes in patients that they were not directly responsible for, they perceived depression as undermining identity while DBS provided the means to regain it. Effects caused by depression were seen as neither authentically generated by the patients nor in their best interests. On the other hand, effects caused by deep brain stimulation could provide patients with a sense of broader control over their emotions and activities.

Development of narrative

Sample codes: past self vs. present self, narrative, perception of self, identification, reorienting

Narratives are a key feature in maintaining a consistent sense of self. However, the process one takes in integrating their past experiences into a personal narrative speaks to the relationship between those experiences and identity. As such, it does not come as a surprise that narrative formation emerged as a primary theme. Codes referencing negotiation of the self or the process of integrating experiences of DBS for depression into identity were used to indicate development of a narrative.

In the context of DBS for depression, the narrative process begins with the perception of self in a depression framework. As patients were prompted to explain their experiences with depression, it became clear that a sense of alienation was pervasive in comparisons of past self to present self. Patients described being unable to relate to past states, especially if they were considered to be states of perceived wellness. Instead, they noted that depressive states were associated with a sense of consistency and futility.

> *"I have a hard time remembering what it was before. I know- I know cognitively that I responded to the world in a different way, but I don't remember what that felt like." (Pt. A; A-3)*
>
> *"All that seems someone else. Someone else living my life, um, with some sense of purpose and, um, my mind goes right to whoever was doing all of that was misled; somehow that this is this is real and that wasn't… Other than seeing myself from a distance going through those motions. I can't be in it." (Pt. A; A-2)*
>
> *"It was like typically how I feel when I'm that depressed, just feel like someone's dead. Someone really close to me is gone and I like just found out about it. But it could represent me. The person dying could be anything. It could be my previous life I didn't- I don't have anymore. It could be, you know, something that I lost as a result of the whole 13 years of being depressed." (Pt. B; C-13)*

This inability to identify with past states was contrasted by a strong identification with depression, which limited patients' self-concept to their current associations and prevented them from being able to reconnect with their past or present identities. In these instances, depression prevented the integration of experiences into the narrative. Patients who were depressed were alienated or lost from their "real" authentic selves.

Further discussion into the clinical changes initiated by DBS suggested the stimulation resulted in changing the perception of an identity defined by depression. One patient spoke of the impact that this shift had in allowing her to better recognize her sense of identity.

> *"When I was depressed, the depression felt like it was a fixed identity, a piece of me, and I'm working on kind of letting that go…. It's easier to think about it as a process than an identity… I feel more capable of seeing beyond that and experiencing beyond that and, um, there's just an openness. So that can still be there but it's only a part of my whole experience instead of 'it is my whole experience.'" (Pt. A; C-13)*

When asked to elaborate on their experiences with DBS, patients described a process of adapting to new perspectives that were produced by changes in depressive symptoms. Often times, the alienation that patients felt during depressive episodes required a process of renegotiation between the self and experiences at new mental states in order to progress toward a state of wellness.

> *"The first month was like 'wow, this is really different what is this.' Um, not knowing where to land. The second month was 'this comes with a whole lot of reactivity and moods that are probably normal but I'm not sure I want.' And the third one is 'okay I think I got this. I don't know what the future is going to hold but I'm okay with, um, pursing out depression and my response to my emotions.'" (Pt. A; C-13)*

Patients felt the need to reform their narratives that were interrupted by depression. They described the process of integrating their experiences, which had been influenced by depression and DBS, into a cohesive narrative identity. In doing so they were able to integrate their experiences into their identities.

> *"I'm trying to become reacquainted. It's like I've been kind of alienated from myself. So, it's like trying to reconnect, so to speak." (Pt. B; E-40)*

> *"It's kind of like redefining myself, you know, I'm not a working nurse practitioner. And I don't have those responsibilities and I don't have that identity anymore." (Pt. D; E-4)*

> *"So, there's a purpose. There's been a purpose to being ill. I've learned- I've learned so many things. I want to put them in action." (Pt. B; C-3)*

The process of reclaiming the narrative ends with how patients see themselves when they achieve wellness. This redevelopment is in conjunction with identity negotiation, where continuous reflection and negotiation promotes the pursuit of one's idealized self. This formation included the recognition of the self as no longer depressed, which required the ability to separate features of self that they connected to with features of depression. Some patients considered themselves depression free by the time data was collected for this project. The subjective nature of identity led to differing relationships between the self and the depression. The progress towards wellness requires understanding how having past experiences with depression influences plans for idealized self. Most patients, however, acknowledged the rebuilding of self.

> *"Interviewer: So, you feel like at this point you can separate what is depression from who is [Patient B]?*
>
> *Patient B: I think so. I think in some part I can." (Pt. B; C-3)*

> *"I think looking back I had to shift my, my understanding of it from an either or. Either I am or I'm not depressed. I'm here or I'm there. To, um, it being more of a bigger experience and, I just have access to more now. And the fact that I can maybe have times when I go back to feeling like that, um, at least right now when I'm there I'm aware that everything else exists still exists, that that's just temporary." (Pt. A; C-23)*

> *"I'm looking over my shoulder less at depression. Um, for a while I was thinking it was, you know, maybe just around the corner or when it felt recent, and, um, wondered if it would come back and, um, I felt attached to it, um, in terms of my history. And I don't feel that anymore. I feel like it's distant and I don't feel like my depression is being managed. I feel like it's not there." (Pt. A; E-25)*

Patients' experiences with DBS for depression ultimately informed their identities. They acknowledged the shift in identity's relationship with depression and DBS as an opportunity for control over their senses of self.

> *"I think it's also just related to my- who I am and who am I if I'm not depressed It's kind of hitting me in a profound way. And then there's an opportunity there to kind of create something." (Pt. A; C-15)*

> *"My identity is forming and I will bring some of who I was in that room with me…. There is almost a level of comfort in going back in that room because I know it so well. But there's another part of me now that said, but you hate that room back there. You hated that. Let's go explore. Let's go and see what else is out here. It's hard to do when you are not sure about who you are as a person without that baggage." (Pt. D; C-18)*

> *"I'm more aware of, of what I can do, and I what I haven't done, and what I want to do." (Pt. E; C-6)*

Relationship with others

Sample codes: "other"; alienation; connection; social roles; negotiation

Theories of identity emphasize the importance of the social in the identification process. This theme encompasses relationships and interactions with others and the surrounding environment, including the identity negotiation process that occurs as a result of these interactions.

Like with the sensation of self-estrangement discussed in the previous theme, all patients experienced Otherness during states of depression. Otherness is the alienation of the social identities of the depressed individuals, rendering them incapable of interacting with others and adhering to the social norms and rules that once constituted their self-concept. It seemed that a source of this alienation was a sense of inward focus during depressive episodes. Patients noted a lack of motivation to connect with others, despite recognizing the value that such connections would have.

> *"I see people flying by. Seems like they're headed somewhere but I don't feel part of whatever they're headed toward." (Pt. A; A-2)*

> *"And not being so self-centered. Just being able to come out of myself and focus on other people. Because it seems like depression makes you almost kind of selfish. Because everything is about me, me, me and how bad I feel and when am I going to feel better." (Pt. B; B-4)*

> *"Like I know it should make me feel reassured or close to someone, but when someone tries to be kind or compassionate it's like it hits a wall. And that, I think, is the hardest of everything." (Pt. A; A-1)*

They indicated that they were aware of the effect that a lack of interaction with others was having on their social relationships, though they couldn't bring themselves to direct their focus to them. This sentiment is connected with others as a feature of wellness, where social connections were seen as part of the identity negotiation process, which help the self to reestablish roles and identify with new ones.

One patient noted a subtle openness and attentiveness to his surroundings.

> *"I didn't feel secluded from everything like I did before. Even when I go outside on the porch and have coffee, um, it sounds weird, but I feel more connected with and enjoying it and enjoying the view and all of this kind of stuff more than I have in the past." (Pt. E; C-12)*

> *"Interviewer: Is it any different being with [your daughter] right now than it was before the surgery?*
>
> *Pt. E: Um, it's- I don't feel as distant from her. I don't as- like there's such a barrier between us." (Pt. E; C-2)*

His statements suggested that the application of DBS shifted his inward focus toward an external one, allowing him to be more aware and open to his surroundings. Here, stimulation produced slight changes in perception, which gave him the opportunity to interact with to his environments and resume the negotiation process.

As this negotiation process picks up again, social roles are expected to change. Therefore, previously established roles, especially those that had complementary roles with others, needed to be renegotiated as social interaction improved.

> *"It took a while for [partner] and I to get back in the rhythm of living together again. Um, and we kind of settled back into that and, um, we each have our moods and [inaudible] it's maybe more of an equal relationship now." (Pt. A; E-11)*

> *"Interviewer: How has the relationship with [Pt. D's partner] changed or not?*
>
> *Pt. D: I think we're still kind of like, she's a little gun shy, like 'is this really real?' Like not really trusting it, and maybe I'm not either. So, we talk about it and realized that it's just going to take some time for us to, to trust that, you know, I'm not going to fall back into the swampy mess I was in and-*
>
> *Interviewer: What is it that you don't trust?*
>
> *Pt. D: Um, well I think we just, we've been away from so long, from each other that it's scary to- it's new." (Pt. D; E-4)*

As these patients saw themselves as heading away from their depression and toward states of wellness, they were likely to have experienced greater social connections with those around them. As a feature of social identities, renegotiation of social roles need to occur in order to maintain a relationship. Therefore, as patients moved away from the traditional behaviors of the sick role, they needed to renegotiate roles with the holder of the complementary caregiver role.

It should be mentioned, though, that while connection with others is a goal for wellness, it also poses a risk for conflict with the expectation of others.

> *"They're probably thinking maybe I wouldn't be -- maybe I'd be better or still not as depressed or still not looking the same or, you know, maybe they probably thought that maybe I wouldn't be as bad off as I was when they last saw me." (Pt. B; C-6)*

Other people's predictions about you or goals for you may not be in line with the goals you have for yourself. Differences in the expectations of a role and the identity patients should have after DBS perpetuates the feeling of guilt for not being better or not being able to be how they thought you would be.

Perception

Sample codes: permanence; futility; hope/hopeless; reality; rationality

Perception, which is understood here as relating to how we view or experience our circumstances and environments, is a major component of depression and the integration of DBS into the concept of identity. The concept of identity is dependent on the interpretation of experiences, which are then integrated into one's identity and used to guide behavior. These interpretations are dependent on the perspectives that shape the integration of experiences into identity. As such, perception can either assist or prevent this process.

As patients experienced DBS for depression, there was general sense of attempting to find balance between hope and hopeless. The process moved from a sense of futility that patients had from years of treatment resistant depression to trusting the positive effects and believing that they could become better.

> *"I suppose maybe a little more hopeful that what I feel isn't going to be permanent. At the same time there's a part of the head that says there's no way that's true. It's going to be here forever." (Pt. A; A-1)*

This shift involves perceiving a sense of control over wellness that is no longer jaded by the negative experiences depression. Patients perceptions regarding their depression change as they undergo deep brain stimulation. One patient described experiencing life when she was depressed as futile and permanent, engaging in a conflict between how she feels versus how she knows she should feel.

> *"It's almost like there's a, something has taken over my reasoning. I know that that's not true. I know there's life and it's not just empty. But I can't get, I can't get beyond that loop in my head." (Pt. A; A-2)*

Sentiments of others seems to follow similar perspectives, in which there was a distinct contrast between the perception of self during depression compared to moments of wellness. Patient perspectives emphasized the continual process of integrating positive outcomes into the illness narrative, working on shifting perception as a process toward wellness.

> *"But I had to learn that that's not true. The depression is awful. The depression makes me feel really awful, not life. Because I have depression doesn't mean that I still don't have things in my life that make it rich, that make it a pleasant experience. Even with the normal ups and downs that come along with it, that has nothing to do with depression." (Pt. B; C-3)*

> *"Focus externally as opposed to internally. Feeling like a part of the world going on around me and a sense that it's okay, as opposed to a sense that there's something wrong. Looking more towards the future instead of this, this current situation." (Pt. A; C-8)*

All patients acknowledged changes in their depression as they underwent deep brain stimulation. As DBS initiated changes in the depression, patients began integrating these new experiences into their narrative, which then altered perception of experience. It was up to the patients to determine how they perceived these changes in relation to their framework of depression. They would say they felt a sense of openness and receptiveness to their surroundings that contrasted to how they experienced life with depression. Overall, patients considered these changes to be a positive outcome, with some mentioning a sense of relief from a persistent lens of depression.

> *"I think that I'd rather have something happen than have nothing happen at all. To not get any response. Because I'm thinking if I can get a really bad response, then maybe I can also get a really good response." (Pt. B; C-3)*
>
> *"Since the turn on, um, distinct difference in life in general. My experience of life is better more alive, more present It's like the world opened up and I'm here for it. It's good." (Pt. A; C-6)*
>
> *"The only thing I can say to describe it is that feels like the world opened up a little bit just for a second. I don't know how else to explain it." (Pt. D; C-16)*
>
> *"I mean, because was depressed for so long there was a dramatic difference, um, I mean just my perception of things and how things made me feel." (Pt. E; C-12)*

Once having experienced positive responses to the DBS, the process of working toward wellness included learning to trust the effects of DBS.

> *"Interviewer: Was it like an on/off phenomenon?*
>
> *Pt. A: Pretty much. You know the day I went home after a whole day of having it on and doing the testing I was exhausted. But the next day I woke up I felt okay. Maybe that's a fluke, the next day I felt good and the next day I felt good that's a good and the longer it's been good I'm trusting that it's persistent and not just something like an imagined affect." (Pt. A; C-6)*

> *"I really think that this past week is just a fluke and it's not the depression. And I think that-- I'm hopeful that I'm going to get better." (Pt. D; C-24)*

There was an increasing sense of progression toward wellness as positive outcomes persisted. This shift included learning how reidentify with the role of depression and negotiate identity accordingly. There was a sense of gaining trust in the positive outcomes of DBS and overriding the doubt, fear, and hesitation that a familiarity that depressive states incited.

It should be noted that the results assume that any changes to depression, and thus identity, were as a result of the DBS. However, it is possible for symptoms of depression to change during its course, sometimes on its own. These results do not account for the changes to depression scores due to medications or other variables that could have affected symptom severity. Regardless, the purpose of these results is not to indicate whether or not the DBS was effective in mitigating depression. Despite the clinical outcomes that occurred as a result of patients' experiences, none of them indicated that they felt the DBS was disruptive or threatening to their sense of selves. If anything, they all found DBS to be either restorative or beneficial to their sense of identity. The summarizing the effects of DBS on depression's effects on identity are as follows:

DBS for depression was desired by patients such that:

1. it mediated the shift from unwell, depressed states to “normal,” well states that were identified by patients’ past notions of self
2. despite its effects on brain states as undermining patient control, its results were seen as positive outcomes that ultimately allowed patients to regain a sense of control over themselves
3. where depression was considered alienating, DBS shifted perspectives in a way that allowed for the identity negotiation process to restart to where patients felt that they could reform their identities and better integrate depression into the narrative
4. it shifted perspective from an inward focus to an outward focus, allowing for patients to more easily connect and build relationships with others
5. it shifted perspective towards a positive attitude about their surroundings in that they were more receptive and able to modify their behaviors to promote desired self-narratives

Discussion

Potential themes

Throughout the analysis process, themes were created from codes identified not only by their potential significance to the ethics discussion on identity in DBS for depression, but also by their repeated presence in the data. It can be assumed that the more relevant data, which ultimately became central themes presented in the results, is due to a greater importance in the conversations between researchers and patients. However, these themes are not conclusive of the entire relevant ethics discussion. There were several potentially significant points mentioned during the interviews by one or two patients on their experiences. Despite not having been discussed thoroughly with all patients, these topics demonstrated a potential for ethical relevance in the discussion of identity in DBS for depression. These potential themes, I will call them, are related to informed consent, enhancement, and identification with the device.

Informed consent

Informed consent is one of the more important ethical concerns at this stage in DBS for depression research. The issue relates to how depression might affect concepts of self, such that it may or may not hinder patients from being clear about their personal desires or goals and making decisions that aim to fulfill these goals. This quote was mentioned by Pt. A during a later interview. By this point, she had already stated that she felt as though she was depression free.

> *"I do every once in a while, have a realization of what I agreed to. And that evokes a response like… Someone, someone, a colleague of mine tweeted something about ECT the other day. Someone tweeted that "ECT saved my brother's life" and she replied, um, "I've never needed, but if I ever did, I'd wouldn't hesitate to do it. It's a life saver." And I wanted to reply, but I didn't that you should hesitate. Um, it's a big thing, it's, it's, I*

> *don't know that I hesitated to do this, but in my right mind now, I would, I would be really worried about having someone put something in my brain; the risks of it. So that gives me a pause." (Pt. A)*

Here, she contemplates the capacity for informed consent, particularly as it related to her case. As she considered herself to be now, free of depression and no longer negatively affected by its debilitating symptoms, she expresses that she would hesitate, as one should, to decide to undergo DBS. She does acknowledge though, that at the time of her consenting to the research while she was depressed, she did not need to hesitate to consider DBS for depression.

> *"I didn't care. I, it was death or that. You could shock my brain. I didn't care if I was brain dead after. [I had] Not a lot to lose, but there's a lot to lose now." (Pt. A)*

Her concern raises a fundamental aspect of not only informed consent generally, but also of consent to DBS for depression: the importance of the risk-benefit analysis. Despite the claim that even highly depressed individuals have the mental capacity to make informed decisions, her depression affected her identity in such a way that she felt as though the decision was clear to her. The principle of autonomy dictates that a person has the right to pursue what will bring them happiness. While she was depressed, she had nothing to lose. The way in which her depression impacted her life was that, at the time, she would have considered the potential benefits, the potential to reduce her depressive symptoms, restore her identity, and perhaps allow her the chance for happiness, would have outweighed any potential risk.

Now, however, as she considers herself well, her perceived risk to benefit ratio to participating in DBS for depression would be entirely different, not for one because she no longer considers herself depressed. The potential risks of DBS are much more detrimental to her happiness now that her perspective has shifted. Her point demonstrates the importance of risk-benefit analyses during informed consent processes. It protects autonomy and ensures that all individuals are able to make choices that they see as being of most benefit to them.

Enhancement

The concern with enhancement relates to the back to the concept of normality, introduced in the well-unwell distinction theme. Normality relies on "norms of affective function… delineating what counts as the abnormal state to be corrected and what counts as the normal state to be sought." (Klein et al., 2015). The abnormal state to be corrected is the depressed state, of course. And we determined that the normal state for return to function would mostly be considered as the past self, which was considered to have been well, by the patients. However, we deduced that the most practical goal for clinical purposes would have been a reference to a previously experienced state. But what if patients thought normal was what others experienced. This begs the question: what, or who, determines what normal functioning is?

> *"I don't know if I've ever been at this point before. I think there was always some depression there. I think that's why it feels so different now, why there's some emptiness because before I think it was just less dark, but it was always just still there. I'm not sure." (Pt. A)*

> *"Interviewer: When was the last time you felt like this?*
>
> *PT. A: I didn't. Maybe this is part of getting older too. It's a part of life, but I haven't felt like this before. I don't think. I don't know. Or maybe I was depressed all that time." (Pt. A)*

The patient first states that she is unsure if she has ever been at such a well state before. This immediately discards the "wellness as a past self" determination that we made earlier.

While she may or may not be right in believing that she has never been this well before, what does this mean the DBS did? I suppose it is possible that she could be mistaken to think that she has never been at this point before, but what does this mean for the concept of a baseline function that we can base normal function on? Does it comfort us to grant that she, perhaps, was depressed at that time? Then does this mean that her DBS enhanced her natural cognitive capabilities, and is this permissible?

Identifying with the device

The final potential theme relates to the direct relationship between the self and the device itself. The patient reports a sort of apprehension about being somewhat dependent on an "inorganic" device, a concern that echoes concerns regarding authenticity.

> *"Yeah, it's a reminder. And it's just kind of weird to think that perhaps for the rest of my life I'm not organic. Like I have to be plugged into the wall. You know, that's just kind of odd to keep this going… I couldn't go out into the woods and sustain myself. Id' need to find a power cord. That's just kind of weird. That's the reminder that there's something, um, interventional about this; it's not organic." (Pt. A)*

> *"Pt. A: There's something not natural about, to need to charge a battery.*
>
> *Interviewer: It's a link to your depression also, I'm thinking.*
>
> *Pt. A: Yeah, maybe that's it. A reminder. It's a good thing though. I'm entirely grateful it's there and doing its thing… [the device] is a part of me." (Pt. A)*

The patient notes that the presence of a device that she has to be responsible for managing several times a week is a reminder several times a week that she is, somehow, inauthentic. She acknowledges this inauthentic physical state. Would it be possible for her worries to translate to her brain states being inauthentic?

She also mentions the device as a reminder that the intervention is present. She is displaying concern over the fundamental nature of the DBS. The interviewer in the second quote brings it up: perhaps it is a reminder that she is an individual who has had severe depression. The device is a constant reminder of a period of time she would, perhaps, forget. Part if personal identity dictates that parts of ourself remain our identity, even if we feel ashamed or a lack of self-dignity for it. It should be noted that she has previously stated that the device was a part of her. However, this does not necessarily resolve the mere fact that she may find it difficult to identify with a device.

These three potential themes, while not repeated themes, pose interesting and especially relevant ethical concerns. The lack of inclusion of these themes may have simply been a result of the stage of research that DBS is concerned with at the moment. It does not discount the potential implications that these themes have, especially with regards to identity. These may be topics for further discussion and collaboration in future work. These three topics are not small decisions. It would be interesting to have gained the perspetives of the other patients as they could provide either consensus or counterarguments.

Limitations

Clinical focus

The data collected for this project was taken from an existing study investigating the clinical effectiveness of DBS for depression. As such, it is important to note that the purposes of this project and that of the site study's are different. The site study conducts psychiatric interviews for the purposes of gaining insight into patients' experiences as it is necessary to monitor the progress of depressive symptoms and ensure that the DBS is functioning optimally for the study. It is not an ethics study. As such, the format, questions, etc. of the data is not optimized for ethical analyses.

However, there are some benefits to using data from this site as opposed to colleting my own. One of which is that the site study is a long-term study, spanning up to ten years. As a result, data has already been collected over a several year period, allowing for a longitudinal study that can focus on the effects of identity as it changes in DBS for depression over a period of time rather than at one point in time or at a future point asking about experiences retroactively. It could also be a benefit to having not conducted my own data collection. The data that was provided to me was collected without the knowledge that it would be studied for an ethics project. In some respects, this could mean that my data collection avoided potential conscious or unconscious biases, either from the myself, the researchers, or the patients. I had a certain amount of trust that any concerns were authentic because it would have only been brought up if someone was genuinely concerned.

Non-structured interviews

Since the goal of the site study is to investigate the DBS for depression from a clinical standpoint, interviews were formatted as psychiatric interviews. Researchers were trained psychiatrists who guided the interviews based on their professional judgement. There were no questionnaire sets to ensure data was collected in a consistent manner. This is an issue for my work, which could be benefitted from consistent data sets for a comparative analysis.

No contact with patients

As stated, the data, consisting of videos taken over the course of several months to years, was provided to me for this project by the site study. Therefore, I have had no contact with the patients and have not conducted any interviews for this project. This means that I have had no influence over the data collected.

Self-report

It should also be noted that since the video recordings are of psychiatric interviews, the data focuses on the patient's perspectives. The self-reporting of their experiences provides more focused data than a survey, for example. Further, self-report allows patients to detail their personal experiences. The value of personal narrative has proven to be an important part of my work. Focusing only on personal, first-person perspectives risks the introduction of bias or misleading data since it may be that they are not aware of, or perceive differently, their identity and any changes that occur. In this respect, some aspects of this project might have benefitted from data provided from family members or friends, who could speak to the identity of a patient from a third-person perspective. However, allowing patients to speak of their own identities has proved beneficial for the goal of this project. It protects the interests of the patients and places their considerations at the forefront of ethics discussion and research.

Conclusion

Analyzing patient perspectives during DBS for depression provided valuable insights into how patients' experiences with DBS for depression affected their concepts of identity. Five themes emerged from analysis of psychiatric interviews: well-unwell distinction, control, narrative, relationship to others, and perception. The summarizing the effects of DBS on depression's effects on identity are as follows:

DBS for depression was desired by patients such that:

1. it mediated the shift from unwell, depressed states to "normal," well states that were identified by patients' past notions of self
2. despite its effects on brain states as undermining patient control, its results were seen as positive outcomes that ultimately allowed patients to regain a sense of control over themselves
3. where depression was considered alienating, DBS shifted perspectives in a way that allowed for the identity negotiation process to restart to where patients felt that they could reform their identities and better integrate depression into the narrative
4. it shifted perspective from an inward focus to an outward focus, allowing for patients to more easily connect and build relationships with others
5. it shifted perspective towards a positive attitude about their surroundings in that they were more receptive and able to modify their behaviors to promote desired self-narratives

Based on the data, the outcomes indicated by the themes held the view that patients considered deep brain stimulation to be as restorative to the sense of identity, which had been previously negatively impacted by their depression. By this reasoning, DBS for depression could be ethically permissible because, for those who suffer from depression, the benefits indicated by these themes could potentially outweigh the risks. However, further work must be done to either confirm or argue against the theses suggested by data, particularly as the limitations of the methodology might have affected results. At the minimum, this project identified themes that highlighted changes in identity such that it helps to understand how these changes might impact ethical analyses of DBS for depression. Identity is a primary consideration in ethics discussions of DBS for depression research. Therefore, these relationships play an important role in envisioning outcomes measures and risk-benefit analyses.

References

Abrams, D. (1999). Social identity and social cognition. In D. Abrams & M. A. Hogg (Eds.), Social identity and social cognition (pp. 197- 229). Malden, MA: Blackwell.

Agid, Y., M. Schüpbach, M. Gargiulo, et al. 2006. Neurosurgery in Parkinson's disease: The doctor is happy, the patient less so? Journal of neural transmission 70: 400– 414.

American Psychiatric Association. (2013). Major Depressive Disorder. In *Diagnostic and statistical manual of mental disorders* (5th ed.).

Anderson, R. J., Frye, M. A., Abulseoud, O. A., Lee, K. H., McGillivray, J. A., Berk, M., & Tye, S. J. (2012). Deep brain stimulation for treatment-resistant depression: efficacy, safety and mechanisms of action. *Neurosci Biobehav Rev, 36*(8), 1920-1933. doi:10.1016/j.neubiorev.2012.06.001

Anderson, V. C., Burchiel, K. J., Hogarth, P., Favre, J., & Hammerstad, J. P. (2005). Pallidal vs subthalamic nucleus deep brain stimulation in Parkinson disease. *Arch Neurol, 62*(4), 554-560. doi:10.1001/archneur.62.4.554

Appelbaum, P. S., Grisso, T., Frank, E., O'Donnell, S., & Kupfer, D. J. (1999). Competence of depressed patients for consent to research. *Am J Psychiatry, 156*(9), 1380-1384. doi:10.1176/ajp.156.9.1380

Appleby, B. S., Duggan, P. S., Regenberg, A., & Rabins, P. V. (2007). Psychiatric and neuropsychiatric adverse events associated with deep brain stimulation: A meta-analysis of ten years' experience. *Mov Disord, 22*(12), 1722-1728. doi:10.1002/mds.21551

Armstrong, C. (2011). APA Releases Guideline on Treatment of Patients with Major Depressive Disorder. *Am Fam Physician, 83*(10), 1219-1227.

Baylis, F. (2013). "I Am Who I Am": On the Perceived Threats to Personal Identity from Deep Brain Stimulation. *Neuroethics, 6*, 513-526. doi:10.1007/s12152-011-9137-1

Beauchamp, T. L., Childress, J. F. (2013). *Principles of biomedical ethics*. New York: Oxford University Press.

Beeker, T., Schlaepfer, T. E., & Coenen, V. A. (2017). Autonomy in Depressive Patients Undergoing DBS-Treatment: Informed Consent, Freedom of Will and DBS' Potential to Restore It. *Front Integr Neurosci, 11*, 11. doi:10.3389/fnint.2017.00011

Berlim, M. T., & Fleck, M. P. (2007). Quality of Life and Major Depression. In *Quality of Life Impairment in Schizophrenia, Mood and Anxiety Disorders* (pp. 241-252). Dordrecht: Springer.

Berlim, M. T., Fleck, M. P., & Turecki, G. (2008). Current trends in the assessment and somatic treatment of resistant/refractory major depression: an overview. *Ann Med, 40*(2), 149-159. doi:10.1080/07853890701769728

Berlim, M. T., & Turecki, G. (2007). Definition, Assessment, and Staging of Treatment—Resistant Refractory Major Depression: A Review of Current Concepts and Methods. *The Canadian Journal of Psychiatry, 52*(1), 46-54. doi:10.1177/070674370705200108

Buckingham, D. (2008). Introducing Identity in *Youth, identity, and digital media*. Cambridge, Mass.: MIT Press.

Cavuoto, J. (2013). Depressing Innovation. Retrieved from https://www.neurotechreports.com/pages/publishersletterDec13.html

Coryell, W., Akiskal, H. S., Leon, A. C., Winokur, G., Maser, J. D., Mueller, T. I., Keller, M. B. (1994). The time course of nonchronic major depressive disorder: uniformity across episodes and samples. National Institute of Mental Health Collaborative Program on the Psychobiology of Depression—Clinical Studies. *Arch Gen Psychiatry, 51*(5), 405-410.

Cyron, D. (2016). Mental Side Effects of Deep Brain Stimulation (DBS) for Movement Disorders: The Futility of Denial. *Front Integr Neurosci, 10*, 17. doi:10.3389/fnint.2016.00017

DeGrazia, D. (1994). Autonomous action and autonomy-subverting psychiatric conditions. *J Med Philos, 19*(3), 279-297. doi:10.1093/jmp/19.3.279

de Haan, S., Rietveld, E., Stokhof, M., & Denys, D. (2017). Becoming more oneself? Changes in personality following DBS treatment for psychiatric disorders: Experiences of OCD patients and general considerations. *PloS one*, *12*(4), e0175748. doi:10.1371/journal.pone.0175748

Delaloye, S., & Holtzheimer, P. E. (2014). Deep brain stimulation in the treatment of depression. *Dialogues Clin Neurosci, 16*(1), 83-91.

Dougherty, D. D., Rezai, A. R., Carpenter, L. L., Howland, R. H., Bhati, M. T., O'Reardon, J. P., . . . Malone, D. A., Jr. (2015). A Randomized Sham-Controlled Trial of Deep Brain

Stimulation of the Ventral Capsule/Ventral Striatum for Chronic Treatment-Resistant Depression. *Biol Psychiatry, 78*(4), 240-248. doi:10.1016/j.biopsych.2014.11.023

Dunn, L. B., Holtzheimer, P. E., Hoop, J. G., Mayberg, H. S., & Appelbaum, P. S. (2011). Ethical Issues in Deep Brain Stimulation Research for Treatment-Resistant Depression: Focus on Risk and Consent. *AJOB Neurosci, 2*(1), 29-36.

Elliott, C. (1998). The tyranny of happiness: ethics and cosmetic psychopharmacology. In E. Parens, ed., *Enhancing Human Traits: Ethical and Social Implications*. Washington, D. C.: Georgetown University Press.

Elliot, C. (2006). ''Caring about risks: are severely depressed patients competent to consent to research?,'' in *An Anthology of Psychiatric*, eds S. A. Green and S. Bloch (Oxford: Oxford University Press), 463–465.

Erikson, E. H. (1956). The problem of ego identity. *Journal of the American Psychoanalytic Association, 4*, 56-121. doi:10.1177/000306515600400104

Erikson, E. H. (1959). Identity and the life cycle; Selected papers, with a historical introduction by David Rapaport. New York: International University Press.

Fava, M. (2003). Diagnosis and definition of treatment-resistant depression. *Biological Psychiatry, 53*(8), 649-659. doi:https://doi.org/10.1016/S0006-3223(03)00231-2

Fava, M., & Kendler, K. S. (2000). Major depressive disorder. *Neuron, 28*(2), 335-341.

Fearon, J. (1999). What Is Identity (As We Now Use the Word)?. Unpublished manuscript

Fenoy, A. J., Schulz, P. E., Selvaraj, S., Burrows, C. L., Zunta-Soares, G., Durkin, K., Zanotti-Fregonara, P., Quevedo, J., Soares, J. C. (2018). A longitudinal study on deep brain stimulation of the medial forebrain bundle for treatment-resistant depression. *Translational Psychiatry, 8*(1), 111. doi:10.1038/s41398-018-0160-4

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International journal of qualitative methods, 5*(1), 80-92.

Fisher, C. E., Dunn, L. B., Christopher, P. P., Holtzheimer, P. E., Leykin, Y., Mayberg, H. S., Lisanby, S., H., Appelbaum, P. S. (2012). The ethics of research on deep brain stimulation for depression: decisional capacity and therapeutic misconception. *Ann N Y Acad Sci, 1265*, 69-79. doi:10.1111/j.1749-6632.2012.06596.x

Fivush, R. (2011). The development of autobiographical memory. *Annu Rev Psychol, 62*, 559-582. doi:10.1146/annurev.psych.121208.131702

Ford, P. J., & Kubu, C. S. (2006). Stimulating debate: ethics in a multidisciplinary functional neurosurgery committee. *J Med Ethics, 32*(2), 106-109. doi:10.1136/jme.200X.013151

Frank, M. J., Samanta, J., Moustafa, A. A., & Sherman, S. J. (2007). Hold your horses: impulsivity, deep brain stimulation, and medication in parkinsonism. *Science, 318*(5854), 1309-1312. doi:10.1126/science.1146157

Gallagher, I. I. (2000). Philosophical conceptions of the self: implications for cognitive science. *Trends Cogn Sci, 4*(1), 14-21.

Gilbert, F., Viaña, J. N. M., & Ineichen, C. (2018). Deflating the "DBS causes personality changes" bubble. *Neuroethics*. doi:10.1007/s12152-018-9373-8

Glannon, W. (1998). Moral Responsibility and Personal Identity. *American Philosophical Quarterly, 35*(3), 231-249.

Glannon, W. (2008). Deep-Brain Stimulation for Depression. *HEC Forum, 20*(4), 325-335. doi:10.1007/s10730-008-9084-3

Glannon, W. (2009). Stimulating brains, altering minds. *J Med Ethics, 35*(5), 289-292. doi:10.1136/jme.2008.027789

Glannon, W. (2014). Philosophical reflections on therapeutic brain stimulation. *Front Comput Neurosci, 8*, 54. doi:10.3389/fncom.2014.00054

Goering, S. (2014). Is it Still Me? DBS, Agency, and the Extended, Relational Me. *AJOB Neuroscience, 5*(4), 50-51. doi:10.1080/21507740.2014.951782

Goering, S., Klein, E., Dougherty, D. D., & Widge, A. S. (2017). Staying in the Loop: Relational Agency and Identity in Next-Generation DBS for Psychiatry. *AJOB Neuroscience, 8*(2), 59-70. doi:10.1080/21507740.2017.1320320

Grisso, T., & Appelbaum, P. S. (1995). The MacArthur Treatment Competence Study. III: Abilities of patients to consent to psychiatric and medical treatments. *Law Hum Behav, 19*(2), 149-174.

Haselager, P. (2013). Did I Do That? Brain–Computer Interfacing and the Sense of Agency. *Minds and Machines, 23*(3), 405-418.

Haste, H. (2004). Constructing the Citizen. *Political Psychology, 25*(3), 413-439. doi:10.1111/j.1467-9221.2004.00378.x

Hoare, C. H. (2002). Erikson on development in adulthood: New insights from the unpublished papers. New York: Oxford University Press.

Hogg, M. A. (2003). Social identity. In M. R. Leary & J. P. Tangney (Eds.). Handbook of self and identity (pp. 462-479). New York: Guilford Press.

Jimenez, F., Velasco, F., Salin-Pascual, R., Hernandez, J. A., Velasco, M., Criales, J. L., & Nicolini, H. (2005). A patient with a resistant major depression disorder treated with deep brain stimulation in the inferior thalamic peduncle. *Neurosurgery, 57*(3), 585-593; discussion 585-593. doi:10.1227/01.neu.0000170434.44335.19

Johansson, V., Garwicz, M., Kanje, M., Schouenborg, J., Tingstrom, A., & Gorman, U. (2011). Authenticity, depression, and deep brain stimulation. *Front Integr Neurosci, 5*, 21. doi:10.3389/fnint.2011.00021

Kehily, M. J. (2009). What is identity? A sociological perspective. In: ESRC Seminar Series: The educational and social impact of new technologies on young people in Britain, 2 Mar 2009, London School of Economics, UK.

Keller, M. B., Lavori, P. W., Mueller, T. I., & et al. (1992). Time to recovery, chronicity, and levels of psychopathology in major depression: A 5-year prospective follow-up of 431 subjects. *Archives of General Psychiatry, 49*(10), 809-816. doi:10.1001/archpsyc.1992.01820100053010

Kessler, R. C., & Bromet, E. J. (2013). The epidemiology of depression across cultures. *Annu Rev Public Health, 34*, 119-138.

Klaming, L., & Haselager, P. (2013). Did My Brain Implant Make Me Do It? Questions Raised by DBS Regarding Psychological Continuity, Responsibility for Action and Mental Competence. *Neuroethics, 6*(3), 527-539. doi:10.1007/s12152-010-9093-1

Klein, E., Brown, T., Sample, M., Truitt, A. R., & Goering, S. (2015). Engineering the Brain: Ethical Issues and the Introduction of Neural Devices. *Hastings Cent Rep, 45*(6), 26-35. doi:10.1002/hast.515

Klein, E., Goering, S., Gagne, J., Shea, C. V., Franklin, R., Zorowitz, S., . . . Widge, A. S. (2016). Brain-computer interface-based control of closed-loop brain stimulation: attitudes and ethical considerations. *Brain-Computer Interfaces, 3*(3), 140-148. doi:10.1080/2326263X.2016.1207497

Kraemer, F. (2013). Authenticity or autonomy? When deep brain stimulation causes a dilemma. *J Med Ethics, 39*(12), 757-760. doi:10.1136/medethics-2011-100427

Kraemer, F. (2013). Me, Myself and My Brain Implant: Deep Brain Stimulation Raises Questions of Personal Authenticity and Alienation. *Neuroethics, 6*, 483-497. doi:10.1007/s12152-011-9115-7

Kroger, J. (2007). Identity development: Adolescence through adulthood. Thousand Oaks, CA: SAGE Publications.

Kumar, R., Lozano, A. M., Sime, E., & Lang, A. E. (2003). Long-term follow-up of thalamic deep brain stimulation for essential and parkinsonian tremor. *Neurology, 61*(11), 1601-1604. doi:10.1212/01.wnl.0000096012.07360.1c

Lapid, M. I., Rummans, T. A., Poole, K. L., Pankratz, V. S., Maurer, M. S., Rasmussen, K. G., Philbrick, K., L., Appelbaum, P. S. (2003). Decisional capacity of severely depressed patients requiring electroconvulsive therapy. *J ECT, 19*(2), 67-72.

Leentjens, A. F., Visser-Vandewalle, V., Temel, Y., & Verhey, F. R. (2004). [Manipulation of mental competence: an ethical problem in case of electrical stimulation of the subthalamic nucleus for severe Parkinson's disease]. *Ned Tijdschr Geneeskd, 148*(28), 1394-1398.

Levy, N. (2007). Neuroethics Challenges for the 21st Century. Cambridge: Cambridge University Press.

Lipsman, N., & Glannon, W. (2013). Brain, mind and machine: what are the implications of deep brain stimulation for perceptions of personal identity, agency and free will? *Bioethics, 27*(9), 465-470. doi:10.1111/j.1467-8519.2012.01978.x

Locke, J. (1689). *An essay concerning human understanding, and a treatise on the conduct of the understanding*.

Lozano, A. M., Mayberg, H. S., Giacobbe, P., Hamani, C., Craddock, R. C., & Kennedy, S. H. (2008). Subcallosal cingulate gyrus deep brain stimulation for treatment-resistant depression. *Biol Psychiatry, 64*(6), 461-467. doi:10.1016/j.biopsych.2008.05.034

Loftus, E. F., & Pickrell, J. E. (1995). The formation of false memories. *Psychiatric Annals, 25*(12), 720-725. doi:10.3928/0048-5713-19951201-07

Malone, D. A., Jr., Dougherty, D. D., Rezai, A. R., Carpenter, L. L., Friehs, G. M., Eskandar, E. N., . . . Greenberg, B. D. (2009). Deep brain stimulation of the ventral capsule/ventral striatum for treatment-resistant depression. *Biol Psychiatry, 65*(4), 267-275. doi:10.1016/j.biopsych.2008.08.029

Mayberg, H. S., Liotti, M., Brannan, S. K., McGinnis, S., Mahurin, R. K., Jerabek, P. A., . . . Fox, P. T. (1999). Reciprocal limbic-cortical function and negative mood: converging PET findings in depression and normal sadness. *Am J Psychiatry, 156*(5), 675-682. doi:10.1176/ajp.156.5.675

Mayberg, H. S., Lozano, A. M., Voon, V., McNeely, H. E., Seminowicz, D., Hamani, C., . . . Kennedy, S. H. (2005). Deep brain stimulation for treatment-resistant depression. *Neuron, 45*(5), 651-660.

McLeod, S. A. (2008). *Erik Erikson | Psychosocial Stages - Simply Psychology*. Retrieved from http://www.simplypsychology.org /Erik-Erikson.html

McCrae, R. R., & Costa Jr, P. T. (1997). Personality trait structure as a human universal. *American Psychologist, 52*(5), 509-516. doi:10.1037/0003-066X.52.5.509

Mecacci, G., & Haselager, W. F. G. (2014). Stimulating the Self: The Influence of Conceptual Frameworks on Reactions to Deep Brain Stimulation. *AJOB Neuroscience, 5*(4), 30-39. doi:10.1080/21507740.2014.951776

Miller, F. G., Fins, J. J. (2006). Protecting human subjects in brain research: a pragmatic perspective. In: Illes J, editor. Neuroethics: defining the issues in theory, practice, and policy. Oxford: Oxford University Press.

Müller, S., and M. Christen. (2011). Deep brain stimulation in Parkinsonian patients—Ethical evaluation of cognitive, affective, and behavioral sequelae. AJOB Neuroscience 2 (1): 3–13.

Munhoz, R. P., Picillo, M., Fox, S. H., Bruno, V., Panisset, M., Honey, C. R., & Fasano, A. (2016). Eligibility Criteria for Deep Brain Stimulation in Parkinson's Disease, Tremor, and Dystonia. *Can J Neurol Sci, 43*(4), 462-471. doi:10.1017/cjn.2016.35

Muroff, J. R., Hoerauf, S. L., & Kim, S. Y. (2006). Is psychiatric research stigmatized? An experimental survey of the public. *Schizophr Bull, 32*(1), 129-136. doi:10.1093/schbul/sbj003

National Institute of Mental Health (n.d.) *Depression*. Retrieved from https://www.nimh.nih.gov/health/topics/depression/index.shtml

National Institute of Mental Health (2018). *Major Depression*. Retrieved from https://www.nimh.nih.gov/health/statistics/major-depression.shtml

Nichols, S. B., & Bruno, M. (2010). Intuitions about personal identity: An empirical study. *Philosophical Psychology*, *23*(3), 293-312. https://doi.org/10.1080/09515089.2010.490939

Olson, Eric T., "Personal Identity", *The Stanford Encyclopedia of Philosophy* (Summer 2017 Edition), Edward N. Zalta (ed.), URL = <https://plato.stanford.edu/archives/sum2017/entries/identity-personal/>.

Oyserman, D., Elmore, K., Smith., G. (2012). Self, Self-Concept, and Identity in *Handbook of self and identity*. New York, NY.: Guilford Press.

Patterson, T. (2017, December 07). My Brain Implant Saved Me From Depression. Retrieved from https://www.huffpost.com/entry/depression_b_4559861?guccounter=1

Perlmutter, J. S., & Mink, J. W. (2006). Deep brain stimulation. *Annu Rev Neurosci, 29*, 229-257. doi:10.1146/annurev.neuro.29.051605.112824

Peppe, A., Pierantozzi, M., Altibrandi, M. G., Giacomini, P., Stefani, A., Bassi, A., . . . Stanzione, P. (2001). Bilateral GPi DBS is useful to reduce abnormal involuntary movements in advanced Parkinson's disease patients, but its action is related to modality and site of stimulation. *Eur J Neurol, 8*(6), 579-586.

Putzke, J. D., Wharen, R. E., Jr., Wszolek, Z. K., Turk, M. F., Strongosky, A. J., & Uitti, R. J. (2003). Thalamic deep brain stimulation for tremor-predominant Parkinson's disease. *Parkinsonism Relat Disord, 10*(2), 81-88.

Rudnick, A. (2002). Depression and competence to refuse psychiatric treatment. *Journal of Medical Ethics, 28*(3), 151. doi:10.1136/jme.28.3.151

Sartorius, A., Kiening, K. L., Kirsch, P., von Gall, C. C., Haberkorn, U., Unterberg, A. W., Henn., F. A., Meyer-Lindenberg, A. (2010). Remission of major depression under deep brain stimulation of the lateral habenula in a therapy-refractory patient. *Biol Psychiatry, 67*(2), e9-e11. doi:10.1016/j.biopsych.2009.08.027

Serpe, R. (1987). Stability and change in self: A structural symbolic interactionist explanation. Social Psychology Quarterly, 50, 44-55.

Schermer, M. 2011. Ethical issues in deep brain stimula- tion. Frontiers in Integrative Neuroscience 5: 17. doi:10.3389/fnint.2011.00017.

Schechtman, M. (2010). Philosophical reflections on narrative and deep brain stimulation. *J Clin Ethics, 21*(2), 133-139.

Schlaepfer, T. E., Cohen, M. X., Frick, C., Kosel, M., Brodesser, D., Axmacher, N., Joe, A., Y., Kreft, M., Lenartz, D., Sturm, V. (2008). Deep brain stimulation to reward circuitry alleviates anhedonia in refractory major depression. *Neuropsychopharmacology, 33*(2), 368-377. doi:10.1038/sj.npp.1301408

Schüpbach, M., Gargiulo, M., Welter, M. L., Mallet, L., Behar, C., Houeto, J. L., . . . Agid, Y. (2006). Neurosurgery in Parkinson disease: a distressed mind in a repaired body? *Neurology, 66*(12), 1811-1816. doi:10.1212/01.wnl.0000234880.51322.16

Souery, D., Papakostas, G. I., & Trivedi, M. H. (2006). Treatment-resistant depression. *The Journal of clinical psychiatry, 67 Suppl 6*, 16-22.

Stets, J. E., & Burke, P. J. (2000). Identity theory and social identity theory. Social Psychology Quarterly, 63, 224-237.

Stets, J. E., & Burke, P. J. (2012). A Sociological Approach to Self and Identity in *Handbook of self and identity*. New York, NY.: Guilford Press.

Stroupe, K. T., Weaver, F. M., Cao, L., Ippolito, D., Barton, B. R., Burnett-Zeigler, I. E., Holloway, R. G., Vickrey, B. G., Simuni, T., Follett, K. A. (2014). Cost of deep brain stimulation for the treatment of Parkinson's disease by surgical stimulation sites. *Movement Disorders, 29*(13), 1666-1674. doi:10.1002/mds.26029

Stryker, S., & Burke, P. (2000). The past, present, and future of identity theory. Social Psychology Quarterly, 63, 284-297.

Tajfel, H., & Turner, J. (2004). The social identity theory of intergroup behavior. In J. Jost & J. Sidanius (Eds.), Political psychology: Key readings (pp. 276-293). New York: Psychology Press.

Taylor, Charles. 1989. The Sources of the Self: The Making of the Modern Identity. Cambridge, MA: Harvard University Press.

Tekriwal, A., & Baltuch, G. (2015). Deep Brain Stimulation: Expanding Applications. *Neurol Med Chir (Tokyo), 55*(12), 861-877. doi:10.2176/nmc.ra.2015-0172

Timmons, M. (2013). *Moral Theory: An Introduction*: Rowman & Littlefield Publishers.

Thoits P.A. (2003) Personal Agency in the Accumulation of Multiple Role-Identities. In: Burke P.J., Owens T.J., Serpe R.T., Thoits P.A. (eds) Advances in Identity Theory and Research. Springer, Boston, MA

Thoits, P. A., & Hewitt, L. N. (2001). Volunteer work and well-being. *Journal of health and social behavior*, 115-131.

Wardrope, A. (2014). Authenticity and autonomy in deep-brain stimulation. *J Med Ethics, 40*(8), 563-566. doi:10.1136/medethics-2013-101419

Weaver, F. M., Follett, K., Stern, M., Hur, K., Harris, C., Marks, W. J., Jr., . . . Group, C. S. P. S. (2009). Bilateral deep brain stimulation vs best medical therapy for patients with advanced Parkinson disease: a randomized controlled trial. *JAMA, 301*(1), 63-73. doi:10.1001/jama.2008.929

Wegner, D. (2003). The illusion of conscious will. Cambridge: MIT Press.

Witt, K., Kuhn, J., Timmermann, L., Zurowski, M., & Woopen, C. (2013). Deep Brain Stimulation and the Search for Identity. *Neuroethics, 6*, 499-511. doi:10.1007/s12152-011-9100-1