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Looking through the lens of stigma: Understanding and anticipating concerns about the responsible development and use of psychiatric electroceutical interventions (PEIs)

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Abstract

Psychiatric electroceutical interventions (PEIs) show promise for treating depression, but few studies have examined stakeholders' views on them. Using interview data and survey data that analyzed the views of psychiatrists, patients, caregivers, and the general public, a conceptual map was created to represent stakeholders' views on four PEIs: electroconvulsive therapy (ECT), repetitive transcranial magnetic stimulation (TMS), deep brain stimulation (DBS), and adaptive brain implants (ABIs). Stigma emerged as a key theme connecting diverse views, revealing that it is a significant factor in the acceptance and usage of PEIs. Stigma not only discourages seeking mental health services for depression but also inhibits the acceptance of PEIs. Addressing the pervasive and complex effects of stigma highlights the need to change societal attitudes toward mental illnesses and their treatments and to provide support to patients who may benefit from these interventions. The map also demonstrates the value of conceptual mapping for anticipating and mitigating ethical considerations in the development and use of PEIs.

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Keywords

Stigma; Depression; Neuromodulation; Electroceuticals

1. Introduction

Depression is estimated to affect about 5% of the world's population, and is considered by the World Health Organization to be the leading cause of disability worldwide (WHO, 2021). In the US alone, major depressive disorder (MDD) is prevalent among 8.4% of adults and 17% of adolescents (NIMH, 2022). More recently, the prevalence of depression has increased by 25% in the wake of the COVID-19 pandemic (Brunier and Drysdale, 2022). In spite of its prevalence, however, depression, along with other mental disorders, continues to be under-resourced and undertreated (Thornicroft et al., 2017; Mahomed, 2020). One of the most persistent barriers to mental health care is the stigma associated with mental health conditions, which discourages individuals experiencing mental health disorders from pursuing, initiating, and continuing treatment for fear of encountering discrimination and exclusion (WHO, 2022). Stigma also has structural effects, undermining opportunities for people with mental illness, and reinforcing the inequitable distribution of resources for mental health services, which are already chronically and systematically underfunded (Livingston, 2020). Examples of structural stigma include the lack of parity¹ in healthcare coverage, state legislations that restrict the civil rights of individuals with mental illness, and the failure to fund mental health research at levels comparable to other health conditions (Corrigan et al., 2014).

Psychiatric electroceutical interventions (PEIs) use electric or magnetic pulses to the brain, and are intended primarily to be used in cases where patients have not experienced remission of their depression symptoms through using medication and/or psychotherapy. While stigma affects many mental health interventions, PEIs are particularly affected by it. Fueled in part by past historical abuses as well as inaccurate portrayals in popular media (Synofzik and Schlaepfer, 2010), fear and suspicion of psychiatric treatments persist, in spite of robust scientific evidence regarding the safety and efficacy of those PEIs currently approved. Stigma toward PEIs is a problem because it undermines public acceptance, hindering access to interventions like electroconvulsive therapy (ECT), which have had a high rate of success in alleviating chronic and treatment-resistant varieties of depression (Mathew et al., 2019). As such, there is a pressing need to better understand the far-reaching effects of stigma in shaping stakeholders' attitudes and beliefs about using PEIs to treat MDD. Such an understanding is useful not only to obtain a sense of which factors might interfere with help-seeking behavior, but also to understand how mental health professionals and the general public can further destigmatize the use of such treatments for mental health conditions.

Over the course of four years, our research team has sought to identify stakeholders' views toward PEIs in the treatment of depression and to understand the factors that shape various

¹Although in the US there is currently parity at the federal level thanks to the Mental Health Parity and Addiction Equity Act (MHPAEA), which requires that health insurance plans cover mental health and substance use disorder treatments at the same level as they cover physical health treatments, often states do not have accompanying state parity laws, making enforcement difficult.

perceptions of their characteristics, including levels of invasiveness, their risks and benefits, their effects on the self, and barriers and ethical issues arising in their use. In this paper, we discuss the results of a conceptual mapping endeavor that we conducted with the aim of drawing out the broader challenges raised by PEIs. The map showcases the role of stigma in connecting the different themes we have been exploring in relation to PEIs, and was developed based on an analysis of our interview and survey data with the aim of clarifying the interrelations among our quantitative and qualitative results. The development of the map was also informed by relevant considerations in the neuroethical literature and by sociological studies that have discussed the role of stigma in public health. Ultimately, our analysis located stigma at the center of participants' perceptions, confirming, on the one hand, clinical perception of stigma as a major obstacle in PEI use, and, on the other hand, showcasing its centrality in non-clinician views of PEIs. Here, it is important to emphasize that we are not claiming that stigma explains all of the concerns regarding PEI use, or is the sole factor that underlies ethical questions raised by these therapies. However, we do argue that the concept of stigma serves as a valuable lens through which to gain a new perspective on these issues, one that is not yet adequately recognized in the literature on these therapies.

2. Methods and mapping

Conceptual maps serve as useful tools for challenging assumptions, identifying new patterns, establishing connections, and visualizing gaps in existing knowledge (Wandersee, 1990). Moreover, mapping is valued for its capacity to synthesize the ideas of diverse communities, acknowledging the social dimension of knowledge construction (Kane and Trochim, 2007). In our project, we specifically employed conceptual mapping to capture the multiple ways in which neurotechnologies used for depression are understood and experienced by different stakeholders in the United States. By taking into account the broader societal context in which PEIs exist, mapping enabled us to identify overarching ethical concerns that may not have been apparent through a narrower analysis of our results (e.g. limited to specific populations or technologies). Placing our data within a cartographic framework allowed us to examine the overall landscape suggested by our empirical findings and leverage its richness to uncover interrelationships within and across different datasets.

Our qualitative data included semi-structured interviews with psychiatrists ($n = 16$), individuals living with depression ($n = 16$), and members of the general public with no diagnosed psychiatric disorder ($n = 16$) from Michigan (Bluhm, 2021, 2023a; Cabrera, 2022; Cabrera and Laura, 2021a, 2021b, 2021c). We used quotas for gender and race in each group to ensure demographic diversity, as well as a quota for PEI experience. Our survey data included responses to our online survey with an embedded video vignette experiment from four USA national samples: the general public ($N = 1022$), caregivers for people with depression ($N = 1026$), patients living with depression ($N = 1050$), and board-certified psychiatrists ($N = 505$) (Bluhm et al., 2023b; Cabrera et al., 2023a; Tyron et al., 2023). We randomly assigned subjects to one of eight conditions in our full factorial design: four neuromodulation interventions by two depression severity levels [moderate or severe].

Our process began by individually mapping the themes that were prominent in our qualitative and quantitative data. Creating individual maps for each theme gave us the

opportunity to consider how these parts were related to each other when arranged together on the same visual plane. During this first phase, our analysis focused on identifying recurrent concerns across five thematic areas: (1) overall attitudes toward PEIs, which included our participants' immediate emotional responses, (2) participants' assessment of potential barriers to and ethical concerns with PEI use, (3) perceptions of PEIs' risks and benefits, (4) perceived levels and kinds of invasiveness, and (5) evaluation of PEI influence on the self. After mapping each theme, our analysis then focused on tracing and developing potential connections among these themes.

Through an iterative process, we were able to pinpoint stigma as a 'connective tissue' that brought together several of the themes that we have explored in relation to PEIs. The results of our mapping revealed stigma to be not only a recurrent issue but also at the center of participants' perceptions, underlying, in particular, non-clinicians' views on the potential effects that PEIs might have (Fig. 1). Stigma turned out to be particularly relevant to how PEIs might be thought to interfere with the lives of people using these treatments, and with various aspects of the self, while being relevant to existing barriers and additional ethical concerns regarding safety, effectiveness, and informed consent.

Our mapping also confirmed psychiatrists' perception of stigma as a major factor in PEI acceptance, with stigma viewed as driving considerable misconceptions and fear regarding PEIs. These connections were discovered and sustained not only through cross-analysis of our quantitative and qualitative data, but also through concurrent comparison of our findings with the broader neuroethical literature, which has, albeit sporadically, discussed the role of stigma in the under-recognition of brain dysfunction in mental health (Mathew et al., 1999), and in the difficulties experienced by patients using PEIs to treat brain disorders (Agid et al., 2006; Baylis, 2013).

It is important to note that the role of stigma has not been extensively explored in the neuroethics literature, nor discussed in regards to PEIs. Thus, we turned to social science studies that have demonstrated its crucial role in mental health treatment. This body of scholarship helped us center stigma in our map, and better situate the cultural, institutional, and other societal factors that influence, and are influenced by, stigma.

3. Results and discussion

The results of our mapping process provide additional insights into our interview and survey data by showing how the stigma associated with mental health conditions and with PEIs influence how our participants viewed the variety of topics we asked them about. Interpreting our empirical findings through the lens of stigma reveals how stigma related to the barriers preventing access to PEIs; to the ethical issues PEIs are thought to raise; to the perception of the risks and benefits of these treatments, as well as their invasiveness; and to the ways in which they are believed to affect the self.

3.1. Stigma and mental health

In his foundational work, Erving Goffman defines stigma as a "deeply discrediting attribute," which positions the stigmatized individual as "a discredited person facing

an unaccepting world” (Goffman, 1963). Bruce Link and Jo Phelan extend Goffman’s definition by conceptualizing stigma as a process by which human differences are identified and labeled, and by which differentiated groups are categorized and stereotyped, a process that results in their disapproval, exclusion, and discrimination (Link and Phelan, 2001). For the latter authors, stigma is inseparable from the exercise of social, economic, and political power. In the context of public health, stigma has been identified and studied in relation to a number of health conditions, such as HIV (Karver, 2022), obesity (Brewis, 2014), epilepsy (de Boer et al., 2008), substance abuse (Buchman et al., 2017), eating disorders (Puhl and Young, 2015), and a variety of mental disorders (Pescosolido et al., 2013). Across conditions and populations, stigma constitutes a chief obstacle in securing fair and equitable health outcomes by reinforcing social hierarchies, disrupting close relationships, limiting opportunities for social participation, reducing resource availability, worsening health-related stress, and inhibiting effective psychological and behavioral responses needed to seek help, engage in care, and adhere to treatment (Stangl et al., 2019). In the last decades, comprehensive frameworks (Birbeck et al., 2019; Pescosolido et al., 2008) have been proposed to address the widespread and pernicious effects of health-related stigma across conditions and across populations in an effort to curb its impact, and to interrupt stigmatization processes where possible. The value of such efforts cannot be underestimated, since stigma constitutes a major driver of population health inequities (Hatzenbuehler et al., 2013).

Mental health conditions, in particular, carry considerable stigma, subjecting those who suffer from them to discriminatory behavior and harmful stereotyping that portrays them as dangerous, incompetent, and weak in character (Corrigan and Watson, 2002). Depression, in particular, tends to be stigmatized as a “fictitious” disorder for which the patient bears considerable responsibility (Aromaa et al., 2011). One reason for this perception might be that depressive symptoms are often believed to stem solely from a person’s behavior and psychological characteristics (Krendl and Freeman, 2019). Certainly, behavioral and psychological factors are relevant to the development of depression, as are social and biological influences; depression is best conceived of as resulting from a complex interaction between biological, environmental, and social factors (Nabeshima and Kim, 2013). However, it is not uncommon for people to hold overly simple views of depression, and to overestimate the extent to which patients can be held responsible for the factors influencing their mental health. These views are present even among friends and family members of individuals with depression, who consider them lazy, less engaged, more isolated, and not easy to engage in conversation (Thornicroft et al., 2007). It is important to acknowledge as well that the stigma of depression intersects with social categories of race, gender, and socioeconomic status, such that stigma impacts populations differently, exacerbating barriers of access for some groups more than for others (Eylem et al., 2020). Nevertheless, the overall effects of stigma on help-seeking are concerning, given that stigma is correlated with low perceived need for care (Mojtabai et al., 2011) and might lead patients to avoid, delay, refuse or discontinue treatment (Clement et al., 2015).

Pursuing or receiving mental health treatment can itself become a stigmatizing experience for patients (Vogel et al., 2007). Although the stigma that accompanies mental health treatment has been recognized in the literature, the stigma that is specifically attached to

medical interventions has only begun to be explored as a conceptually distinct category (Madden et al., 2021). Intervention stigma, as it is coined by Erin Madden, refers to the stigma associated with medical interventions in which features of treatment may also drive prejudice and discrimination toward patients and health practitioners who administer them (Madden, 2019). The factors that underlie intervention stigma might be tied to the medical condition it is intended to address (e.g. medications for drug addiction) or they might operate independently (e.g. abortion and cosmetic surgery). With PEIs, we find that their stigma is, simultaneously, related to characteristics specific to PEIs as well as to the negative social beliefs and attitudes that surround depression. Regarding the former, there seems to be an immediate aversion to the bioelectrical mechanism of PEIs as well as substantial resistance to their contemporary use, given the associations of these treatments with the controversial history of psychosurgeries such as frontal lobotomies (Valenstein, 1986).

3.2. Stigma toward psychiatric electroceutical interventions

A recent framework developed by the National Institutes of Mental Health (NIMH) allows us to conceptualize the stigma of PEIs as a wide process that extends in all directions of society, and occurs along three socio-ecological levels: structural, interpersonal, individual (NIMH, 2021). In line with that framework, we characterize stigma at the top as a macro-process driven by wide cultural norms that regulate the meaning of treating depression through a PEI, social factors that shape popular views towards neurotechnologies, as well as regulations, funding, policies, and laws that determine access to them. We also see stigma as an interpersonal dynamic in which users of PEI interventions might experience enacted stigma, that is, encounter prejudice and discrimination in their interactions in private and public spaces and feel devalued, dehumanized, and disrespected by their relatives, friends, colleagues, employers, and insurers. On this level, we can also find the stigma associated not only with patients who make use of neurotechnologies but also with those responsible for their care as well as the health professionals that provide such services. In our last level of analysis, we conceptualize stigma at the bottom as a micro-process in which stigma affects persons at an individual level, and refers to a person's cognitive, affective, and behavioral responses to facing or experiencing stigma. In this case, persons who may use, currently use or have used PEIs to treat their depression might fear others' perceptions of them, and, as a result, refuse it as an option or discontinue it if treatment has been initiated.

In this section, we explain how stigma functions as a centering concept for the major themes of our work on stakeholder views around PEIs. Our data suggests that stigma permeates general stakeholder attitudes, functioning as a distorting lens through which PEIs are appraised (especially by non-clinicians) making stigmatized PEIs seem more dangerous, more risky, more invasive, and having more drastic effects on the self than the available evidence suggests is actually the case. Stigma also shapes ethical considerations about perceptions of safety and effectiveness, and appears to intensify already existing barriers to their use. While stigma plays a critical role in non-clinicians' appraisal of PEIs' various characteristics, our clinical respondents noted, in particular, the considerable influence of both the stigma related to mental illness as well as the stigma associated with PEIs, especially with ECT.

It is important to acknowledge, however, that in spite of how integral stigma is to stakeholder views on PEIs, in our survey we did not find an explicit identification of stigma as a key barrier or as an ethical concern among the non-clinician groups (Bluhm et al., 2023b). We hypothesize that one of the reasons for this is a lack of awareness among our non-clinician participants of the term “stigma” beyond its implicit form. Stigmatizing attitudes might be present, even in the absence of a conceptual awareness of what stigma is. A helpful distinction made in the mental health literature is one between explicit and implicit stigma, with the former referring to conscious negative evaluations, while the latter involve automatic negative appraisals “that are not otherwise captured by typical explicit measures because individuals may be reluctant to report them, or because they exist outside of awareness” (Peris et al., 2008). The existence of stigma, both explicit and implicit, may be correlated with low levels of mental health literacy, the latter understood as “knowledge and beliefs about mental disorders which aid their recognition, management, or prevention” (Jorm et al., 1997). Stigmatizing labels attached to mental disorders might even create additional difficulties to properly recognizing their symptoms and, thus, providing appropriate help and support (Tuijnman et al., 2019).

3.3. Barriers

In a previous qualitative study, we conceptualized stigma as an attitudinal barrier to initiating and continuing treatment (Cabrera, 2022). Here we conceptualize stigma more broadly as a complex barrier for PEIs, where the term ‘complex’ is intended to capture the compounding effect of a double stigma – the stigma associated with the condition and the stigma attached to the intervention. While the stigma of depression might discourage patients from seeking treatment in the first place, the stigma of treatment might exaggerate the negative effects of using PEIs, at the expense of their potential and actual benefits. For instance, the belief that depression is not a “real” affliction might lead individuals to minimize or disregard the risks of untreated depression, whereas a highly effective procedure like ECT might be avoided because it is believed to cause permanent memory loss. In that sense, persistent negative social attitudes toward mental health treatments are related but not reducible to the stigma attached to mental disorders, since the former vary considerably among interventions.²

Out of the standard treatments for depression, pharmacological therapies constitute the more stigmatized modality (Kwintar, 2005; see also Castaldelli-Maia, 2011). Although depression continues to be generally undertreated (NIMH, 2022), there is evidence to suggest that psychotherapy, when compared with medications, is still a preferred treatment option among patients (Hetlevik et al., 2019). However, individuals considering psychological help for depression are often perceived to lack positive qualities like confidence and emotional stability when compared to individuals not pursuing treatment or those seeking to treat physical ailments like back pain (Ben-Porath, 2002). These beliefs are even more pronounced for patients who opt for pharmacological treatment for depression (Angermeyer et al., 2017). In fact, the stigma associated with medication use is one of the factors

²This can also work the other way around, that is, the choice of treatment can also affect the perception of the condition it is meant to treat. In a comparison of online comments on articles covering pharmaceutical versus neurosurgical interventions, comments about the latter were less critical than comments about the former (Cabrera et al., 2019). We suggest that a reason for this was because people believe that neurosurgery is unlikely to be used unless the condition is serious or “real” enough.

behind poor patient adherence, with more than half of patients diagnosed with MDD failing to take medications as prescribed (Dell’Osso et al., 2020). Although nonadherence rates for depression are in the same range as for many other chronic illnesses (World Health Organization, 2003), the reasons for nonadherence may not be the same, with stigma related to the treatment, rather than just to the disorder, playing a significant role in nonadherence to antidepressant therapy. For example, a study examining the differences between the stigma of depression and the stigma of antidepressants found that whereas the former does not impact patient adherence to medication, the latter does, due to the association of antidepressant use with emotional weakness and inability or unwillingness to deal with personal problems (Castaldelli-Maia, 2011). Deeply entrenched misconceptions around antidepressants pertain to their real or perceived lack of therapeutic efficacy, the side effects of long-term use, as well as the fear of addiction and psychological dependence. These common and widespread beliefs continue to create aversion for many patients who, even after diagnosis, believe that they can easily overcome mental illness on their own or manage it by implementing lifestyle changes (Marasine, 2021).

Similar considerations around efficacy, long-term use, and dependence seem to underlie attitudes toward electroceuticals, which also face similar challenges to pharmacotherapy in that they carry a troubled history tainted by historical abuses as well as widespread negative representation in the media and popular culture (Lauber et al., 2005). However, there is a crucial difference in the way that PEIs can become stigmatized, and that pertains to their use of electrical or magnetic pulses to modify neural function. Of our PEIs, ECT was the most stigmatized intervention, due to the controversial and direct use of electricity in the brain, general aversion to invasive treatments in psychiatry, perceived relationship with epilepsy (itself a stigmatized condition) as it produces a seizure, and the association of electrical stimulation with punishment, torture, and social control (Wilhelmy et al., 2018). Again, an additional reason why ECT is so heavily stigmatized is, in part, due to its historical association with coercive procedures attached to practices of brain surgery to treat psychiatric conditions, specifically the use of lobotomies and similar somatic psychiatric interventions in the last century (Johansson et al., 2013). This is an association shared by DBS, as an early version of it was infamously used in the 70s by psychiatrist Robert Heath as a form of “conversion therapy” on a gay male patient (O’Neal et al., 2017). Another relevant historical precedent is the use of psychosurgery to treat other poorly defined behavioral disorders like aggression and violence (Neumaier et al., 2017). It is also important to note the influence of the anti-psychiatric movement which treated practices in biological psychiatry as medically dubious and ethically suspect (Rissmiller and Rissmiller, 2006). These negative associations have had a lasting influence in the public imagination as it is exemplified by the persistence of films like *One Flew over the Cuckoo’s Nest* as cultural referents (Cabrera et al., 2021b).

Stigma is responsible for misconceptions about these treatments and contributes to the lack of knowledge and understanding of their effectiveness, leading to significant barriers to their use. In addition, these misconceptions persist as the latter elicit strong emotional reactions that are challenging to correct. In our survey, we measured stakeholders’ immediate affective responses to various PEIs, and found that compared to the severely stigmatized ECT, participants felt more positively toward rTMS, which carries less stigma, and felt less

positively about DBS and ABIs, which, in addition to being more medically invasive, share with ECT the stigma of psychiatric surgery. The stigma surrounding PEIs then results in patients not receiving treatments when they would benefit from them, further perpetuating poor mental health outcomes.

3.4. Ethical issues

A number of the ethical concerns about PEIs that were identified in our interviews and survey reflect the stigma associated with these treatments. Even though ECT and rTMS are currently approved in the US by the Federal Drug Administration, limited evidence of effectiveness remains an important ethical issue for our non-clinician respondents. Stigma might be partly responsible for this apprehension, operating in the background of our participants' perceptions. As Arnaez and colleagues (Arnaez et al., 2020) point out, individuals may be unaware or unwilling to admit that stigma is affecting their treatment decisions, and may see it as more acceptable to attribute their treatment to practical factors (structural, attitudinal) than with concerns about what others might think. Respondents from the psychiatrist group did, in fact, confirm the existence of stigma as a significant ethical issue as well as its role as a barrier in the use of ECT, related to patients not getting the treatment when it would help them as one of the most concerning effects (Bluhm et al., 2023b).

Poor mental health literacy, lack of awareness, lack of knowledge, and the influence of stigma is also reflected in participants' other ethical concerns about PEIs. Participants also saw as an issue not having enough information to provide fully informed consent. Negative attitudes toward some PEI treatments might create a profound aversion that prevents patients and the general public from accessing and understanding the information that they need, while the stigma around depression continues to shape societal beliefs about how depression affects an individual's decisional capacities (Klein et al., 2016). Though some of the literature has identified cognitive deficits resulting from major depression, especially those impacting decision-making (Hindmarch et al., 2013), as well as considerable attitudinal shifts (Cabrera, 2011), a recent qualitative analysis of the experiences of female patients receiving ECT highlights the difficulty of separating the effects of the illness from the effects of stigma, especially when the latter intersects with other social identities (Clarke et al., 2018). In short, the ethical concerns surrounding PEIs are heavily influenced by stigma associated with mental health conditions and their treatments.

3.5. Risks and benefits

Stigma also influences perceptions of the risks and benefits of PEI treatments. Perceptions of risk are shaped by cultural values and norms, and by societal factors such as media coverage and social networks (Slovic, 2007). To the extent that these factors foster and propagate stigma, perceptions of a treatment's positive and negative effects are likely to be shaped by it. Once again, it is important to maintain a conceptual separation between the stigma that surrounds depression from the stigma that affects treatments for depression, even though in practice they are interrelated. While the stigma of depression might discourage individuals from accurately appraising the risks of untreated depression, the stigma associated with PEIs might make these therapies appear riskier than the evidence suggests. For instance,

permanent loss of memories has been a repeated concern with ECT among patients and the general public, yet formal risk assessments have only documented transient disturbances in recent memories (Reisner, 2003). Though it is true that these studies do not settle the question of whether memory problems occur with ECT (Sadowsky, 2017), ECT is still currently considered by psychiatrists to be the most effective and quickest intervention for treatment-resistant depression (Wade et al., 2016), yet due to persistent stigma, it is still underutilized (Ma et al., 2020). Furthermore, psychiatrists express greater concern about the risks of untreated MDD than about the risk of temporary loss of short-term memory (Cabrera et al., 2021a).

The stigma attached to procedures like ECT might also influence the assessment of other PEI interventions in ways that are, ultimately, counterproductive. Knowledge of older procedures such as ECT and lobotomy can constitute a frame of reference for the general public in making sense of newer interventions in psychiatry, including DBS and rTMS (Cabrera et al., 2019). For instance, a recent study found that rTMS patients mentioned that the pain and side effects associated with ECT influenced their expectations of rTMS, noting the differences between the two therapies (Ontario Health, 2021). At the same time, rTMS seems to be less stigmatized than ECT. Indeed, negative side effects of rTMS were perceived as “more acceptable” than those of ECT, in spite of the fact that the effects on neural tissue are still not well understood (Terranova et al., 2019). Furthermore, these framing effects can result in the hasty acceptance of novel treatments when these are viewed as more “modern” or “humane” versions of older interventions. While stigma might deter the use of effective PEIs, like ECT, for depression, it can also hype the potential benefits of other neurotechnologies, especially of implantable ones which have already received positive press coverage (Cabrera et al., 2018). In combination with the hype created around the novelty of neural devices, disability- and depression-related stigma might foster premature acceptance of experimental technologies and the choice to use a PEI might appear as an “opportunity” that no reasonable person would refuse (Wardrope, 2014).

3.6. Invasiveness

Stigmatized treatments might be also perceived as more invasive than non-stigmatized modalities. In our interviews, we learned that our stakeholders consider a treatment’s invasiveness more broadly than it is generally understood in a medical context, taking into account not only how physically invasive a treatment might be, but also how disruptive it might become to their daily activities as well as the degree to which it requires disclosure of their memories, thoughts, emotions, and personal histories (Bluhm et al., 2023a). The fear of being subjected to discriminatory treatment on the basis of a disease or on the basis of using a specific treatment for it might be implicit in stakeholders’ perceptions of invasiveness. Using a PEI might not only interfere with their personal and professional lives but also affect their social standing. A recent qualitative study reported experiences of devaluation and social rejection among ECT patients that resulted from others knowing that they received ECT (Kring et al., 2018). DBS patients, for instance, might be afraid of their own families treating them differently, even viewing them as something other than fully human (Foley, 2015). An already existing concern among DBS users is that family members and others close to them often point to the device as a source of an undesirable emotion or

interpersonal conflict, and they are consequently directed to check or adjust their settings. There is also an additional worry that a surgically invasive procedure like DBS might be emotionally invasive, producing artificial or inauthentic emotions in patients or preventing them from experiencing emotions appropriate to given situations, such as sadness at a funeral (Klein et al., 2016). Once again, it is worth pointing out the overlap between PEIs and pharmaceuticals as the latter have also been perceived to induce “chemical” emotions (Price et al., 2009).

3.7. Self and stigma

A final theme explored in our research is the way that PEIs are understood as having potential effects on the self. Our discussion of this issue is shaped by the neuroethics literature responding to clinical reports to self-related characteristics in patients undergoing DBS therapy. Here, the issue is not that stigma prevents patients from using a PEI, but rather that these changes occur in a context where both the disorder and the treatment carry significant stigma. Yet for the most part, the discussion in the neuroethics literature has occurred largely without any explicit discussion of the relationship between these potential effects and stigma. This is a surprising omission, given how central stigma has been to the way that PEIs – and generally depression treatments – are experienced by our stakeholders. In this section, we show that, despite an initial narrow focus on a specific kind of self-related effect of DBS, attending to stigma can benefit discussion about PEIs and the self. In particular, we place our discussion in context of the published literature on the self, and following the NIMH tri-level framework for understanding stigma as it enables us to capture its multifaceted character.

Much of the early discussions of PEIs and the self in the neuroethics literature have been influenced by instances of dramatic change that result from neurointerventions. These debates, as Pugh has shown, encompass as many positions as there are definitions of the self (Pugh, 2020). One of the first papers discussing this issue, by Marya Schechtman, puzzles over negative reactions among patients with refractory depression to what are otherwise positive changes experienced under DBS. Schechtman argues that the abrupt shift in mood (a patient, for instance, describes how everything in the room became brighter when stimulation began) can be experienced as a threat because these changes can disrupt a patient’s autobiographical narrative “through both the rapidity and manner of change.” Schechtman continues, “the psychological changes brought about are so profound and occur so quickly that they can seem to break off one narrative and start a new one” (Schechtman, 2010). In response to Schechtman’s paper, a number of authors attempted to characterize the nature of this perceived threat to the self, arguing variously that these self-related changes also concern personality, identity, agency, authenticity, autonomy, and selfhood more generally (Gilbert et al., 2021). This way of understanding the issues, however, has a number of important limitations: first, it focuses on dramatic changes that are plausibly the direct result of neuro-stimulation at the expense of more subtle and multifaceted effects; second, it risks making a hasty generalization about these changes, inappropriately attributing the experience of the few to the many; third, it does not allow us to address the relationship between the effects on the self of the PEI and those of the condition being treated; and, lastly, it does not aid in understanding the complex relationships among an

individual's experience of DBS, their personal relationships, and broader social structures influencing their experiences of DBS.

Our earlier discussion of stigma as a process that takes place at the structural, interpersonal, and individual levels helps us address some of these questions, especially in regards to the way that an individual's experience intersects with broader relational and societal considerations. This approach to stigma allows us to capture its various manifestations as a socially constructed phenomenon shaped by cultural norms, discursive practices, and institutional factors; as an interpersonal dynamic defined by discrimination and exclusion; and, lastly, an individual experience to which stigmatized individuals respond through various coping mechanisms. All of these factors influence how patients make sense of their condition and perceive available interventions to treat them. These considerations prompt us to look closely at the social context in which PEI therapies exist, and employ a broader understanding of self-related changes that "takes into account not just stimulation-related effects on the self, but also how patients' understanding is influenced by their experience of life with a disorder, and of their understanding of the disorder and the therapies used to treat it" (Bluhm et al., 2021). The patient's understanding and her experience are not formed in a vacuum; rather, they are shaped by and negotiated with others that exist in a cultural, political, and socio-economic space.

Attention to these broader considerations is compatible with a narrative approach to understanding the self, and indeed, a closer look at the neuroethics literature on the self and DBS suggests a natural fit between this framework and a feminist relational, narrative understanding of the self. Responding to Schechtman's concerns, Francoise Baylis has argued that the best way to understand self-related changes associated with DBS is to think of personal identity in relational terms, that is, as "a dynamic, socially, culturally, politically, and historically situated communicative activity (based in narrative and performance) that is informed by the interests, perspectives, and creative intentions of close and distant others" (Baylis, 2013). Then a more significant threat is not necessarily a device that modifies brain activity, but how others respond and react to persons who turn to these interventions to treat their conditions, particularly "the scope of possible identity-constituting narratives available to persons ... in a society that is not welcoming of persons with physical and psychological disabilities" (Baylis, 2013) This is especially true with interpersonal forms of stigma, which are likely to have negative effects on identity constitution when stigma leads to social exclusion. These interpersonal experiences, in addition, cannot be dissociated from the broader structural factors that spread and perpetuate stigma. Baylis' relational analysis calls us to be attentive to "the vulnerability of those seeking treatment to the attitudes of others, attitudes which ... are structurally embedded in the social and institutional system" (Goddard, 2017). If stigma in the context of mental health is institutionally, culturally, and socially entrenched, and manifested in social interactions, then we would expect stigma to have an adverse effect on any of a person's self-related characteristics.

Indeed, patients with stigmatized conditions often experience damaging effects to various aspects of their personality, identity, agency, autonomy, authenticity, and sense of self (dubbed "PIAAAS" changes by Gilbert et al., 2021) as a result of stigma. The work of Hilde Lindemann is particularly helpful here. Lindemann maintains that moral injury to a

person's identity occurs through infiltrated consciousness, that is, when an individual in a less powerful social group internally adopts oppressive notions of her identity wrought by a more powerful group (Lindemann Nelson, 2001). In the case of depression, its already deleterious effects are likely to worsen if having such a condition results in overall experience of devaluation that, in turn, results in a harm to a person's identity. Negative emotions experienced during depressive episodes already affect information processing and create cognitive distortions that lead individuals to re-assess the self in ways that are consistent with the negative emotion that they are experiencing. One study reports that participants felt less competent and attractive during periods of depression and their identities changed to reflect that affective state (Cast and Welch, 2015). This negative effect is likely to worsen if common stereotypes about depression are internalized; for example, individuals with depression might endorse the stigmatizing belief that their mental health struggles are caused by a weak personality (Yokoya et al., 2018) and might, therefore, feel less inclined to seek support in close relationships and/or reach out for professional help, exacerbating social withdrawal and isolation. Patrick Corrigan (Corrigan et al., 2016) has coined the term the "why try effect" to describe the process by which individuals with mental disorders apply harmful stereotypes to themselves and, as a result, experience a loss of self-respect and a sense of futility.

Additionally, infiltrated consciousness not only injures identity but also constricts agency by narrowing the range of identity-constituting narratives available to a person, an effect that can be materially reinforced by the systemic deprivation of opportunities to exercise agential capacities and gain access to relational and material goods. In the case of depression, the dual effect of condition-stigma and intervention-stigma is especially worrisome because both are already operating in the context of diminished agency caused by disease. Matthew Ratcliffe has argued that depression disrupts agency in such a fundamental manner that action seems impossible rather than just difficult (Ratcliffe, 2015). Cruwys and colleagues conceptualize depression as a deprivation of fundamental processes of social identification that satisfy primal needs for meaning, support, influence, and belonging (Cruwys et al., 2014). These processes might be even more deficient for stigmatized groups, which often feel compelled to conceal their identities (Pachankis, 2007). Phenomenological analysis of depression and social stigma reveals a common experience of rejection, whereby the subject is thrown into a state of persistent alienation, one of "relationless relationality" (Paskaleva-Yankova, 2022). This suggests that stigma likely heightens the negative effects of depression on a person's self-conception by refusing social connection. The malignant social positioning that results from stigma can also impact autonomy, one dimension of the self that refers to "a person's willingness to assert existing preferences or express new ones" (Viaña et al., 2020). Indeed, a recent study shows that when compared with the normal population, patients with treatment-resistant depression exhibited decreased levels of extraversion and openness to experience, and, more importantly, that "patients with pharmacor-esistant depressive disorders, who have had more experience with discrimination because of their mental struggles, showed a poorer response to treatment" (Prasko et al., 2016).

Furthermore, not only can negative social attitudes about depression have a magnifying effect on its symptoms, misconceptions around PEIs that target depression can also have a

considerable effect on the way that patients experience its treatment. Indeed, stigma-related attitudes, for instance, might explain the satisfaction gap reported among ECT patients and physicians, with clinical notions of success differing substantially from the way that patients understand and experience their own recovery. A study conducted by Rose et al., in 2003 famously argued that clinical assessments failed to consider adverse effects on memory reported by ECT patients, especially those related to autobiographic memory (Rose et al., 2003). Though more recent studies have shown that this is not an unfounded concern (Seniuk, 2018; Wells et al., 2021), it seems that many ECT patients value the recovered ability to re-enter work and to re-establish a social life more highly than memory problems that might surface in the course of recovery, which could be potentially managed through cognitive training (Choi et al., 2017). Kring et al. (2018) find that more salient issues for patients were dealing with prejudice toward mental illness and toward ECT as well as the generalized absence of information about the procedure, especially of its life-saving qualities. It is telling that in interviews conducted with ECT patients, those who reported a good experience felt supported by health care providers and were subsequently able to integrate ECT therapy into their own sense of self (Knight et al., 2017). Adequate support to patients who have undergone ECT might mean decreasing the shame and stigma associated with having a psychiatric disorder and receiving ECT for it (Sadeghian et al., 2019), especially among friends and family members who often take on caregiving roles. Stigma, in that sense, can not only precipitate effects on the self in ways that worsens the effects of an illness but also hinder patient recovery. It remains to be seen, however, whether and how the experiences of patients who have been treated with ECT are similar to those of patients who use other PEIs. We believe that this is a promising line of inquiry for future research.

4. Limitations

Both our conceptual map and the empirical research project on which it is based have some limitations. First, the researchers and research participants all live in the United States, and all (at least to some extent) are influenced by this social and cultural context, including the Western/American understanding of depression as involving the symptoms outlined in the *Diagnostic and Statistical Manual of Mental Disorders* and, more broadly, as a medical, at least partly biological disorder. Second, because our aims in creating this map were to draw connections among our qualitative interview data, our survey data, and the literature, as well as to organize an array of diverse concepts in a way that gives insight into the ethical issues raised by PEIs, we were not able to do full justice to the nuances of our findings. In particular, this means that we have not addressed here the variability in our participants' views, both with regard to the different PEIs we included in the study and with regard to the different stakeholder groups. At a group level, the biggest differences were seen between the psychiatrists, on the one hand, and the three non-clinician groups, on the other. We do note these differences at several points in the paper, and they are discussed in greater detail in the publications presenting our interview and survey data (see reference list for details).

5. Conclusion

Conceptual mapping has been a valuable representational strategy in extending our range of vision “to see beyond the flat topography and uncover the geography of ideas that remain unseen” (Kane and Trochim, 2007). In our case, this means that a map has enabled a panoramic view of our quantitative and qualitative results, such that the centrality of stigma in shaping stakeholder views towards PEIs has become apparent. The normative value of this mapping has been to identify, help us anticipate, and increase awareness of the ethical challenges that arise in the use and development of PEIs for depression, especially in relation to the pressing question of whether the treatment can lead to problems that are perceived to be worse than the disease. Our map makes clear how stigma is a determining factor in how neurotechnologies used in the treatment of depression are understood and experienced by multiple relevant stakeholders in a way that has not been considered by the existing literature. Our results also show how stigma influences perceptions of an intervention’s risks and benefits, level of invasiveness, existing barriers and ethical concerns. Stigma is relevant as well to the current debate in neuroethics about the effects of PEIs on the self; one of the specific ways in which that is the case is that patients with stigmatized conditions often encounter and internalize negative stereotypes. These stereotypes can be attached to the condition itself and to its treatments, as is the case with depression. However, no mapping endeavor is able to represent all of the relevant features of a topic comprehensively, as emphasizing some features of the overall terrain necessitates de-emphasizing others. Although mapping allowed us to examine the overall terrain suggested by our empirical results, and draw on its richness to posit interrelations within and across our data sets, not all of our data found a place within our map. For instance, although stigma does constitute a major obstacle to treat depression in general and more so to treat it with any of these neurotechnologies, the map does not explain how access is affected by the lack of federal legal framework, the lack of consensus in clinical guidelines, and geography. In addition, stigma tends to amplify what are perceived to be negative characteristics of PEIs, but this obscures the fact that our respondents did see benefits to using PEIs such as precision in targeting relevant areas of the brain and that it works through a non-addictive mechanism.

Understanding how stigma aggravates an already debilitating condition, how it imposes additional barriers to effective treatment, and how it jeopardizes patient recovery highlights the need to improve social conditions that would effectively support the therapeutic effect of PEIs, where one has been proven.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Dr. Achtyes declares the following Competing Financial and Non-Financial Interests, he has served on advisory boards for Karuna, Alkermes, Janssen, Lundbeck/Otsuka, Roche, Sunovion and Teva. Dr.

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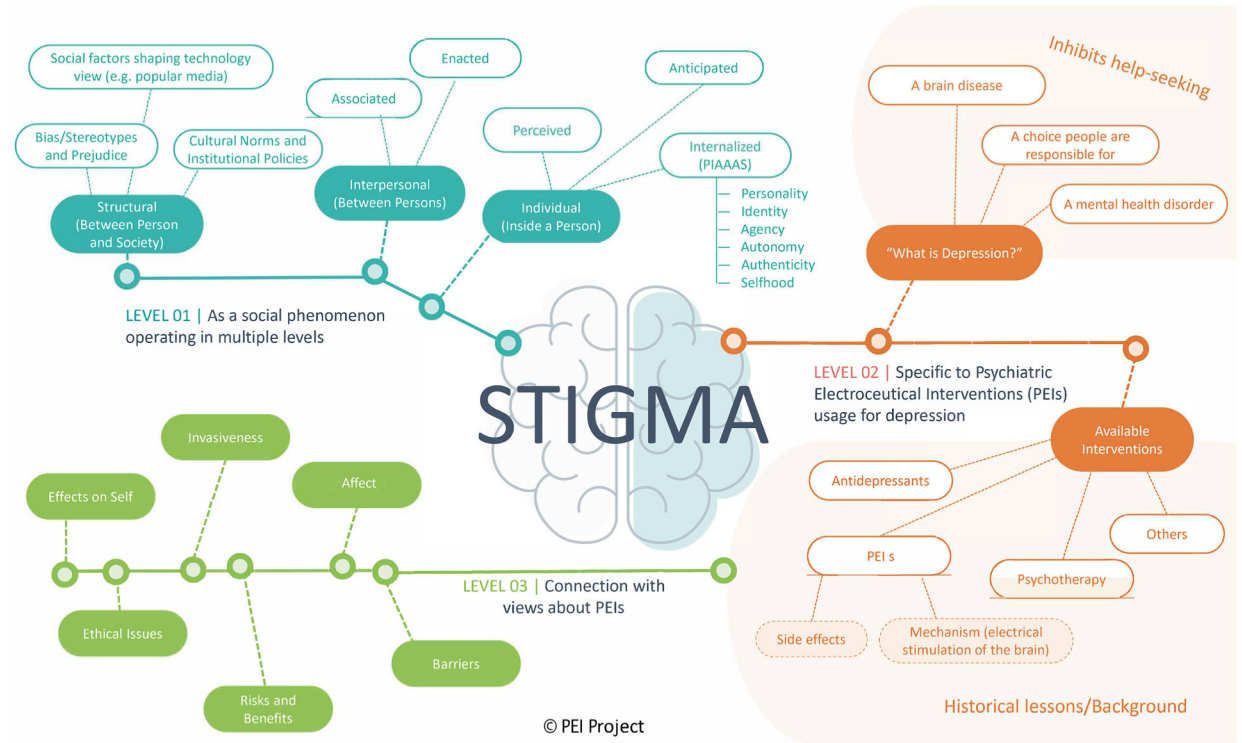


Fig. 1. Map representing stigma as a central theme across a variety of ethical, societal, and technological considerations raised by PEIs as a treatment of depression.