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# How Relationships Matter: The Need for Closer Attention to Relationality in Neuroethical Studies

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Deep brain stimulation (DBS)—a neurosurgical procedure in which electrodes are used to stimulate regions of the brain—is being investigated as a therapy for treatment-resistant depression. Lawrence and colleagues (2019) note that this experimental therapy is the subject of controversy within neuroethics. In particular, they reference worries that depressive patients' beliefs and decisions concerning DBS may be compromised. They highlight possibilities that patients may be unable to cogently evaluate the benefits and drawbacks of DBS; may make decisions out of desperation; or may, due to media portrayal, have inflated hopes about the effectiveness of DBS (Lawrence et al. 2019). In evaluating these ethical concerns, the authors also consider the possibility that patients' beliefs and decision-making processes may be affected by *relational vulnerabilities*, that is, vulnerabilities arising from the effects of patients' interpersonal relationships (Lawrence et al. 2019).

To gain insight into these issues, Lawrence and colleagues interviewed 24 patients with treatment-resistant depression so as to assess their "interest level, hopes, fears, and decision-making process" with respect to DBS (2019, 211). The authors conclude that, at least with respect to their study, the aforementioned ethical concerns may be overstated: "Participants seemed very aware of the risks, and very aware of their own difficulties processing information, and there was no indication that participants would make quick decisions to undergo deep brain stimulation" (217).

In this commentary, we question the authors' approach to investigating the role of relational vulnerabilities in patients' beliefs and decision-making processes. First, we argue that the authors' conclusion—i.e. that ethical concerns may be overstated—is unwarranted. We argue further that their conception of and approach to investigating relational vulnerability are overly narrow in scope. Finally, we suggest that their analysis could have benefited from reflexively considering relational vulnerabilities arising from their own study protocol.

The authors identify two forms of relational vulnerability, which we address in turn. The first, described in

a paper by Bell et al. (2014), is the vulnerability a research participant experiences as a result of asymmetrical power relations existing between investigators and participants. In the context of studies on DBS for depression, the relevant power asymmetries arise from patients' "active depressive symptoms, less knowledge about the device, and less understanding of alternatives" (Lawrence et al. 2019, 216). Let's call this form *power-relational vulnerability*.

In their analysis of power-relational vulnerability, the authors consider patient responses to the following interview question: "Receiving a deep brain stimulator is an important decision. Many people would want to discuss it before making a decision. If you were offered a deep brain stimulator, who is the most important person you would want to help you with that decision?" (Lawrence et al. 2019, 211). Many patients ( $n = 14$ ) stated that they would consult multiple providers, family members, and Internet resources. From this, the authors infer that patients "seemed to respond to [power-relational vulnerability] by expanding the number of people participating in the decision-making process" (Lawrence et al. 2019, 211).

Based on the authors' analysis, one might be tempted to draw the following conclusion: Given that patients would seek others' advice in making decisions about DBS, we have less reason to worry than we otherwise would about the impact of power-relational vulnerabilities. Indeed, such a conclusion might seem the natural one to draw in the context of the authors' overarching claim that ethical concerns related to patient decision making are overstated. However, to warrant such a conclusion, we would need to know more than the mere fact that patients would seek advice from others. We would need to know whether and under what conditions patients think such advice would be helpful—and whether it would in fact *be* helpful—in mitigating power-relational vulnerabilities. The authors could, for instance, have addressed this question by asking patients whether they had sought advice when making past medical decisions, and how this advice impacted their sense

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of vulnerability. Had the authors done so, they might have found that, in certain contexts, external advice increased patients' confusion, rendering them *more* vulnerable. Were this the case, we would have more reason to be concerned about power-relational vulnerability, not less. Or the authors might have found that advice from others did mitigate patients' sense of vulnerability, but only in certain contexts.

Another shortcoming concerns the authors' definition of power-relational vulnerability. As work in feminist bioethics has shown (Ells 2003; MacKenzie and Stoljar 2000), power asymmetries beyond those that arise in dyadic investigator–patient relationships are ethically relevant to patients' decision making. For example, structural power dynamics based on gender, class, race, and—with particular relevance to this study's population—disability and mental health status can affect patients' relationships not only with investigators, but also with medical professionals, friends, family members, and caregivers, with significant impacts on patients' beliefs and decision making (McLeod and Sherwin 2000). Had the authors been operating with this broader conception of power-relational vulnerability, their analysis would likely have revealed vulnerabilities that are difficult to detect without being specifically attuned to socio-structural forces.

The second form of relational vulnerability the authors discuss (and which they attribute to MacKenzie and Walker [2015]) is the vulnerability that arises from how a person's (evolving) self-identity both shapes and is shaped by their relationships with others. For example, whether someone identifies as risk-averse might be influenced by how supported they feel in their close relationships. Let's call this form *identity-relational vulnerability*.

The authors dedicate only one paragraph to their discussion of identity-relational vulnerability. In this paragraph, they consider whether having a DBS might increase a patient's identity-relational vulnerability. If a DBS "changes how a person feels and acts," this could impact their relationships and therefore their self-identity (Lawrence et al. 2019, 216). The authors then interpret one patient's concern about potential stigma—"that people would view her as 'crazy,' or would otherwise be put off by knowing she sought an 'extreme treatment' [i.e., a DBS]"—as a concern about identity-relational vulnerability (Lawrence et al. 2019, 217).

The authors' analysis unfortunately stops there. They don't trace out any implications for what that patient's concern might tell us about the role of identity-relational vulnerability in decision making (aside from that it plays a role). This shortcoming might be partly due to the fact that the authors included no direct questions addressing identity-relational vulnerability in their interviews. To provide a more robust analysis, the authors might have explicitly asked questions addressing connections between patients' relationships and their self-identity. For example, they might have asked how patients think family, friends, and others have helped (or hindered)

them in understanding who they are during a depressive episode, or while trying a new treatment. Doing so might have allowed for a deeper analysis, and could have yielded data that would help medical practitioners and investigators support decision-making processes for future patients. For instance, had they learned that patients tend to depend significantly on others for maintaining their sense of identity in times of uncertainty (as Lindemann [2013] suggests), this might be reason to increase the role of family members and caregivers in informed consent processes. Given that the authors did not include any targeted questions, their discussion of identity-relational vulnerability seems underdeveloped, and the added potential to positively impact future patients (and guide future research) is left unrealized.

The authors might resist our calls for additional interview questions, pointing out that it's infeasible, given time and resource constraints, to include all relevant questions and consider every salient issue in a single study. However, we hope our arguments have shown that certain additional questions are necessary if the authors want to avoid misleading conclusions, and to do justice to their important goal of analyzing relational vulnerabilities. Yet we also believe that the authors' analysis could be strengthened even before adding more questions. For instance, to address power-relational vulnerability, the authors might have reflexively considered the impact of power asymmetries on their own study. When asked where they would turn for more information about DBS, multiple patients ( $n=5$ ) said they would turn to the interviewer: "[addressing the interviewer] 'Well, you're the person who introduced it to me and explained it to me, and you're obviously interested in it. I would assume you're somewhat knowledgeable in it'" (Lawrence et al. 2019, 215). The respondent to this question is explicitly referencing informational power asymmetries between themselves and the investigator, asymmetries that could impact beliefs and decision making. A closer analysis of such answers could provide relevant information about the role of power-relational vulnerability, even before increasing the number of questions.

The authors' investigation of relational vulnerability is a step in the right direction. But by neglecting to ask certain key questions, address the complexity and multidimensionality of relational vulnerability, and reflexively consider the impact of power asymmetries on their own study, the authors risk drawing misleading conclusions, and fail to do justice to their important goals of analyzing the role of relational vulnerabilities in patients' beliefs and decision making, and, more generally, of contributing to the debate on the ethics of DBS for treatment-resistant depression. ■

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# Consent for Deep Brain Stimulation in Depression: A Perspective From Investigators

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Lawrence and colleagues (2019) take a thoughtful approach to an important ethical question and make a meaningful contribution to ongoing studies related to deep brain stimulation (DBS) for treatment-resistant depression (TRD). Reasonable concerns have been raised about the ways in which severe depression may compromise a person's ability to give fully informed consent for an experimental surgical treatment, and the authors here explore this issue directly with patients similar to those who have enrolled in DBS trials.

Lawrence and colleagues interviewed depressed inpatients with an acute worsening of mood who had read a brief description of DBS. Of course, individuals who enroll in DBS trials are chronically severely depressed and come to a decision regarding DBS trial enrollment following much consideration (Filkowski et al. 2016). Nevertheless, this study provides an important look at the thought process underlying patient decision making. The themes and individual comments reported by Lawrence and colleagues are quite similar to those from depressed individuals who are being evaluated for participation in the DBS for TRD study at Emory University (clinicaltrials.gov NCT01984710)—from both those who ultimately enroll in the trial and those who decline participation. Depressed patients present for evaluation for study inclusion because they feel they have exhausted all other options, including electroconvulsive therapy. They have stopped being able to participate meaningfully in work or family roles. The sense of having lost a vital part of themselves is often described

as part of their depression and as the thing they most hope that stimulation can recover for them. The hopes and expectations of participants in the DBS for TRD study tend to be more moderate than the hope for remission voiced by many of the study participants interviewed for by Lawrence and colleagues. They wish to feel more connected and engaged with loved ones and to return to more meaningful participation in work or volunteer activities. Almost all express the hope that scientists can learn something from their illness that helps prevent other people from having to experience it. It is not uncommon for patients who enroll in the DBS for TRD study to state an expectation that they will be one of the participants for whom the treatment does not work, even as they hope it does.

It is important to recognize that although prospective DBS participants may have moderate expectations for improvement, this level of improvement is still described as significant. Prospective participants have been so severely ill for so long that almost any degree of improvement is expected to be worth the risk of surgery. The comment from Lawrence and colleagues' study participant who estimates that there is a 95% chance of suicide if ECT stops working is consistent with the outlook of those individuals who seek participation in the DBS for TRD trial. They are not acutely suicidal (and the study protocol precludes inclusion of individuals who are acutely suicidal or have recently made a suicide attempt). However, the future they envision for themselves is one of intolerable pain that cannot be alleviated.

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