



Listening to Patients: A Pillar for the Epistemology of Neurointerventions

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publication of both quantitative outcomes and qualitative descriptions of the experiences of study participants over years. ■

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Listening to Patients: A Pillar for the Epistemology of Neurointerventions

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In their article, “Patients’ beliefs about deep brain stimulation (DBS) for treatment resistant depression,” Lawrence, Kaufmann, DeSilva, and Appelbaum analyze the responses of 24 psychiatric inpatients with treatment-resistant depression to deep brain stimulation (DBS) (Lawrence et al. in press). Their findings indicate that patients have minimal interest in DBS unless they are convinced that their condition is deteriorating or the evidence for its effectiveness strengthens. They express concerns about the DBS surgical procedure and its potential adverse effects. The findings also confirm the worry that patients are vulnerable in making decisions about DBS, i.e., their ability to weigh the risks and benefits is compromised due to depression. In addition, they are prone to maintaining unrealistic expectations due to media influence.

This commentary advances two arguments. First, Lawrence et al.’s analysis challenges the gross and paternalistic overgeneralization that individuals with depression or other mental illnesses lack the capacity to make rational decisions. The interviews illustrate that patients, withstanding their depression, were able to engage in a procedurally rational contemplation about whether they

should accept DBS as a form of treatment, thereby illustrating that they are in fact rational enough to make decisions about their medical care. Second, Lawrence et al.’s analysis has larger implications to how scientific research and clinical care can be co-advanced by making the patients influenced by scientific research programs and clinical treatments a part of the process that evaluates the effectiveness of potential treatments. While recent advances in brain imaging methods as well as increased sophistication in neuroscientific modeling of the brain have facilitated the study of neural mechanisms associated with depression, they provide incomplete information about whether and how novel neurotechnologies can genuinely help patients (Tekin et al. 2017). Including patients’ perspectives to the information grounded in neuroscientific advances is necessary to obtain a complete understanding of the effectiveness of novel neurotechnologies to treat mental disorders and thus benefits both research and the clinic.

There is a commonly held view that individuals with mental disorders lack rational decision-making capacity and thus should not be trusted in making moral decisions as well as decisions pertaining to their care.

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Examples of this widespread presupposition can be found in media and clinical circles. It is not unusual, for instance, right after a horrific homicide, for public and media discourse to raise questions about a suspect's mental health history and whether their alleged mental illness should excuse them from responsibility. It is as if to diagnose someone as mentally ill is to declare that the person is irrational. However, this gross and paternalistic overgeneralization that individuals with mental disorders (of any kind) lack rational decision-making capacity is wrong: there is no conclusive scientific, clinical, or patient based data that supports this view. Rather, findings indicate that depressive symptoms do not necessarily interfere with a person's competence to make informed decisions about selecting treatments or enrolling in research protocols (Appelbaum et al. 1999).

We must acknowledge that patients with mental disorders do suffer from orientational challenges that are associated with the symptoms of the particular disorder such as anxiety, paranoia, sleep deprivation, and cognitive impairments (Tekin 2014; Tekin and Outram 2018). Such disruptions disorient the individual in their relationship with themselves (e.g., inability to sleep may further anxious thoughts about one's self-worth) and others (e.g., increased anxiety may exacerbate the paranoia about what colleagues may be perceiving them). More importantly these orientational challenges may limit patient's epistemic agency—e.g., their understanding of mental disorders and assessments of available treatments—as well as moral agency—e.g., their ability to take responsibility for their actions in social settings. Diminished epistemic and moral agency may complicate individuals' capacity to make treatment related decisions and give informed consent to potential treatments. While these are legitimate concerns about the limitations some mental illnesses may put on epistemic and moral agency, mental illnesses do not necessarily nor universally interrupt person's epistemic or moral agency. Orientational challenges can disrupt both, however, not all conditions create such impairments, and if they do, they do so in varying degrees. In addition, degrees of compromised agency can change over time. Finally, those whose orientational challenges compromise their rational decision making capacity are often only impaired temporarily or situationally. Given such complexity, there is no reason to question a person's decision-making capacity based only on a diagnosis of mental illness.

Lawrence et al.'s interviews with patients nicely illustrate that the presupposition that individuals with mental disorders lack rational decision-making capacity is ungrounded. For example, as discussed above, orientational challenges such as feelings of desperation might impair decision making capacity and the person's ability to assess the information provided may be compromised. However, patients in Lawrence et al.'s study do seem to be acutely aware that depression may compromise their decision-making capacity. They accept this vulnerability in their ability to weigh the risks and benefits of DBS. As

Lawrence et al show, several of the patients feel that they are unable to make a decision about receiving DBS in their present state and their desperation can interfere with their judgment about receiving DBS treatment. But what is really interesting and promising is that these patients have an insight into their condition and they respond to this impediment with appropriate responses (Tekin 2014; Tekin and Mosko 2015). For instance, because they felt unable to weigh the risks and benefits of DBS, they thought they would include more people such as trusted family members in their decision-making process, conduct more research, consult with other professionals etc. Thus, they were able to make good decisions about their illness, dealing effectively with the inherent orientational challenges. As Lawrence et al emphasize, this is also a great way of overcoming the challenges involved in relational vulnerability due to power differentials between patients and medical professionals.

Lawrence et al.'s work has larger implications to advances in scientific research and clinical care because it illustrates that including patients, i.e., the very individuals who are directly influenced by scientific research programs and clinical treatments, benefits the process of knowledge production in medical epistemology. First person reports of individuals with mental disorders, as well as clinical and scientific research focusing directly on patient experiences offer unmatched resources for psychiatric epistemology, especially in the context of current crisis and controversy in mental health research (Poland and Tekin 2017; Tekin 2017; Tekin and Outram 2018). These include, but are not limited to, information on orientational challenges that are associated with having a mental illness such as the psychic pain or other symptoms and signs of the illness that patients encounter; sources of courage and strength in coping with such disruptions in their daily lives; responses to different treatment methods such as the use of psychotropic medications, receiving professional psychotherapy, and joining support groups; feelings about their interpersonal relationships; and patients' own responses to stigma. According to what is called the trilateral strategy scientific and clinical work involving individuals with mental disorders, as well as their first-person reports are pillars of psychiatric epistemology (Tekin 2016). These epistemic resources shed light into developing effective interventions on mental disorders, as they disclose, respectively, what may be the underlying cases of mental disorders, how to effectively treat them, and what it may be like to have someone with a mental disorder. These epistemic sources together are especially important for guiding and assisting interventions in psychiatry because they help to assess therapeutic successes and failures. The information obtained from these first-person perspectives is not exhaustive, however, as Rachel Ankeny argues, the inclusion of patient perspectives allows us to engage with different types of evidence that might be overlooked in conventional case reporting scenarios (Ankeny 2017). Thus, including patients' perspectives to the information

grounded in neuroscientific advances is necessary to obtain a complete understanding of the effectiveness of novel neuro-technologies to treat mental disorders. ■

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What's in a Name? How Deep Brain Stimulation" May Influence Patients' Perceptions

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While the study by Lawrence and colleagues (Lawrence, Kaufmann, DeSilva, and Appelbaum 2019) offers several important insights into the ethical issues related to the use of DBS for depression, a noteworthy yet unmentioned consideration is the effect of the very name of the treatment—*deep brain stimulation*—on the patients' perceptions of the treatment and their ensuing choices. The name *deep brain stimulation* is, of course, not the authors' own; it is standardized within the medical field. However, well-established research has shown that the language used to describe an option influences the subject's perception of that option: the framing effect (Tversky and Kahneman 1981). Thus, it is worth acknowledging the potential framing effects of the standardized description of the treatment as *deep brain stimulation*. This description, like any, is not value neutral; it emphasizes some qualities of the treatment over others and introduces certain connotations through its terminology, both of which potentially impact a patient's considerations regarding whether to pursue deep brain stimulation as a treatment for depression.

The framing effect occurs when people respond to the same set of choices differently based on the way that the choices are described (Tversky and Kahneman 1981). It is one of the many ways in which human beings systematically deviate from rational decision making on account of psychological tendencies or cognitive biases. Researchers from various disciplines, such as behavioral psychology and behavioral economics, have developed a number of studies that have both established the prevalence of the effects and identified factors that enhance or minimize the effects (Piñon and Gambaro 2005). For example, in one now-classic study, participants were given a description of a scenario in which they had to prepare for an outbreak of an unusual disease expected to kill 600 people (Kahneman and Tversky 1981). Participants were given the choice of two programs as a response to the outbreak, but the two programs were described differently to different groups of participants. When a program was described positively in terms of the number of lives saved ("200 people will be saved"),

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