DBS for Depression? Lessons From Patients’ Beliefs for Research, Treatment, and Noninvasive Brain Modulation

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Finally, we agree with the authors that vulnerability remains a main ethical concern. In their discussion, the authors talked about relational vulnerability, but do not address how that relates to the way that they present the information they gave participants about DBS. They also interpret the participants’ desire to consult with other providers, conduct research on the Internet, and involve trusted family members in the decisions as a form of responding to relational vulnerability. However, relational vulnerability deals with a broader view on the power asymmetry between an investigator and a patient, as well as the epistemic gaps patients have regarding these procedures. Thus, participants are vulnerable to how others in society (such as the media and the Internet) may portray these procedures in ways that do not help inform in a meaningful way the participants’ decisions, or in a way that truly addresses those relational vulnerabilities. Yet patients are also vulnerable to how clinicians and researchers approach the topic, and as such the imbalance of power makes issues of decision-making capacity a key area to continue exploring.

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DBS for Depression? Lessons From Patients’ Beliefs for Research, Treatment, and Noninvasive Brain Modulation

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Lawrence and colleagues (Lawrence et al. 2019) present a valuable set of interviews about deep brain stimulation (DBS) with treatment-refractory depression (TRD) patients. Their focus on patients outside an actual DBS setting allows for proactive ethical reflection, informed by the views of respondents who represent the majority of today’s TRD patients. Thereby, the study adds a perspective that has been largely neglected in current empirical neuroethics. Still, we have a twofold concern with their approach and their interpretation of the data.

First, Lawrence et al. fail to differentiate between a—realistic—research context and a—currently hypothetical—treatment context. However, the fears, hopes, and expectations of patients, and also any reasons underlying these beliefs, are likely to differ significantly between these two settings.

Second, the authors introduce DBS to their interview partners in a rather isolated way, to be provided...
independent of any alternative or complementary procedures. However, in any realistic clinical setting (including that of clinical trials), DBS would be combined with other treatment modalities, such as psychotherapy or psychopharmacology, and its take-up has to be judged against other neuromodulation techniques.

Still, the material presented is worthwhile, because it can teach a series of lessons also for the implications of potential noninvasive forms of neuromodulation in TRD and other psychiatric diseases, facilitating ethical thought in these neighboring areas.

DBS IN RESEARCH OR IN TREATMENT

DBS is an established treatment modality for several serious movement disorders, and it is under investigation for a series of psychiatric conditions covering not only depression, but also obsessive-compulsive disorder, anorexia nervosa and other eating disorders, Tourette syndrome, Alzheimer’s disease, and several addictions (Linden 2014). By a first approach, DBS research is required, just like all other research with human participants, to live up to internationally acknowledged standards and guidelines of research ethics, like the Helsinki Declaration, and to corresponding national laws. However, DBS research, particularly for new indications, is facing a set of additional challenges not easily covered by these common rules. It often takes place in the context of “experimental treatment” offered as last resort on an individual basis, and uncertainty about possible outcomes is rather high while the candidates who have to consider this treatment option are in great despair (Nuffield Council on Bioethics 2013). To a certain extent, Lawrence and colleagues’ interview partners reflect these concerns when they are rather reluctant to have a DBS device implanted, showing concerns about the invasiveness, novelty, and limited efficacy of the procedure, or even being outright against being implanted or being “experimented on” (214). At the other end of the spectrum, some participants are extremely positive, expecting almost miraculous cure, and consider DBS to be something “very big” (213).

However, the context in which both these fears and these hopes do apply remains unclear. In our opinion, this context is very important, not just for clinical judgments but also for ethical considerations. If a treatment is supported by strong evidence as to its likely efficacy, patients may still refuse it, for example, because of an exaggerated fear of a less likely (e.g., anesthesia) or minor risk; if a treatment is entirely experimental and only supported by anecdotal evidence, patients may still select it, driven by despair and hope (Johansson et al. 2013). The ethical challenges in these two scenarios will be both difficult and different. For example, for an established treatment with good evidence, even an invasive one, proxy consent for patients who do not have the capacity to think through the risks and benefits of treatment might be justifiable (Glannon 2008), but this would not apply for experimental treatments. Conversely, in a research context, exaggerated hopes of desperate patients might be a reason to exclude them because of their therapeutic misconception and the immorality of exploiting vulnerable patients. Mixing up situations of treatment and research runs the danger of eliciting views that are either exaggerations or understatements (Horstkötter and de Wert under review).

DBS IN ISOLATION OR IN CONTEXT

A number of neuromodulation treatment modalities for depression and other psychiatric conditions are currently under investigation. Apart from DBS, these include the noninvasive brain stimulation techniques, transcranial magnetic stimulation (TMS) and transcranial electric stimulation, and to an increasing extent also self-regulation training with neurofeedback (NF), based on electroencephalography (EEG) or functional magnetic resonance imaging (fMRI) (Mehler et al. 2018). Another related technique is lesion surgery for psychiatric indications, mainly using cingulotomy or anterior capsulotomy (Subramanian et al. 2017). All these techniques aim to alleviate the symptoms of severe depression, or their respective target disease, in a more or less direct way by modulating underlying neural networks. However, they are hardly provided, or investigated, in isolation from more conservative therapeutic approaches covering cognitive-behavior therapy, psychopharmacological drugs, or even electroconvulsive therapy (ECT). Lawrence and colleagues, however, seem to disregard this point. They not only present DBS in a rather isolated manner; they even ask their participants to make a choice between preferences for different treatment modalities. By contrast, combining treatment modalities is the more likely and more feasible scenario in the potential introduction of neuromodulation for depression and other psychiatric conditions. Participants in the current study appear highly anxious that DBS might take away their current therapies and even cut off their way back to these modalities in case DBS turns out ineffective or even worsens their symptoms. Obviously, it is a problem to withhold effective treatments from patients in research settings; however, in the likely case that neuromodulation, if effective at all, will add to rather than fully replace ongoing treatments, this concern might be much less prominent. At the same time, however, researchers should take this message very seriously, and scientific curiosity in upcoming neuromodulation should pay proper attention to the views and experiences of the patients in, with, and for whom these techniques are developed. Their trust is crucial if new means of therapeutic neuromodulation are to be developed.
LESSONS TO BE LEARNED FOR NONINVASIVE NEUROMODULATION

Against this background, Lawrence and colleagues’ qualitative study remains very worthwhile because it gives voice to a group of patients whose views are rarely documented and can also inform research agendas in neighboring areas of neuromodulation. Some complications and concerns, like those linked to invasive surgery, indeed appear unique for DBS (and lesion surgery) contexts, whereas other topics, like concerns about efficacy, adverse outcomes, issues related to diminished agency or transformed identity, and those linked to decision-making capacity are likely to arise also in the context of noninvasive brain stimulation and neurofeedback. It would have been interesting to find out more about patients’ views about multifaceted treatment approaches where neuromodulation is embedded in contexts of behavioral and/or cognitive approaches. Concerns about efficacy are, almost by definition, always present in the context of clinical research, and particularly in clinical settings in which experimental treatment is provided.

With regard to DBS, invasiveness also appears as a prominent point of concern. People fear the surgery and dislike the idea that something gets implanted in their bodies or brains. Intuitively, this might give rise to a preference for noninvasive means of neuromodulation, like TMS and NF. However, without proper research into the perception of invasiveness and the exact reasons for any dislike, we cannot confirm this intuition. Neuromodulation by definition invades the functioning of people’s neural networks, and if applied in psychiatric contexts, it is meant to invade a person’s psychological functioning. This raises the questions of how patients perceive different forms of invasiveness (surgical and psychological or social) and which features (e.g., one-time versus long-term, reversible versus irreversible, visible from the outside versus invisible) trigger any preferences or aversions, and why.

Agency and changes of identity have frequently been discussed in current neuroethical literature on DBS. However, to date it remains unclear whether critical arguments developed in the context of Parkinson’s disease (Glannon 2009) also apply in psychiatric contexts where changes to a person’s identity might become the intended aim rather than an undesirable side effect. Moreover, the concept of psychiatric DBS has been criticized because patients undergo any changes in a passive way, rather than being actively engaged in their own healing process (Focquaert and Schermer 2015). This raises the question of how patients experience their participation in neuromodulation more generally. Does making a decision in favor of TMS and visiting the researcher or physician count as active engagement? Do patients undergoing neurofeedback experience their participation indeed as being actively self-regulated, as is currently assumed in the literature? From the perspective of agency and identity, would this render neurofeedback more ethically justified than any competitors that aim to change the brain even more directly? Alternatively, might patients also feel passively regulated even during neurofeedback, for example, by their clinician’s instructions and expectations or the mechanism of the EEG or fMRI apparatus? (cf. Horstkötter 2015, 2017). Ethical add-on studies or substudies that accompany research in neuromodulation in psychiatry should put these questions high on the agenda, expanding on the research presented by Lawrence and colleagues.

REFERENCES


