

preferences if they change?). The solution of Müller and Christen is to propose a contingent advance directive policy and, more broadly, to bracket these concerns over autonomy by stating that “the ethically decisive question is not whether DBS can alter the personality or not, but whether it does so in a good or bad way.” By default, the answer may come to depend on clinical indication: In DBS for PD with predominantly motor symptoms, clinicians will tend to implicitly privilege the patient’s preoperative personality as more authentic and rational than the postoperative, which is suspicious for a pathological component; in DBS for depression, the reverse will hold true. The dissemination of any more nuanced view will require a public discourse between neurosurgeons and ethicists. As scientific advances in DBS enable treating more patients for more neuropsychiatric conditions, there will be a concomitant impetus for our community to drive the development of neuroethical guidelines and the thoughtful application of philosophy to the everyday concerns of patient autonomy and informed consent. ■

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# Exploring Layers of Meaning with Deep Brain Stimulation Patients

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Tens of thousands of patients have received deep brain stimulation (DBS) implants that aim to treat a variety of movement disorders, including Parkinson’s disease (PD). We share Müller and Christen’s (2011) interests in the effects of DBS that extend beyond treatment of PD symptoms. However, we think that their engagement with the literature on unwanted treatment effects is inadequate to the task of understanding significant consequences for those who

receive the treatment. What is needed is an extensive examination of the embodied experience of DBS treatment *from the patient’s perspective*.

Müller and Christen (2011) uncritically adopt the widely received “principles of biomedical ethics.” In effect, they presuppose which issues are important and thus ignore the crucial dimensions of patient experience. We argue that careful attention to these areas of patient experience

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should inform doctors and ethicists, as well as future DBS recipients. Müller and Christen (2011) are concerned to distinguish side effects in terms of their measurement and impact on quality of life, yet these distinctions have little force outside of the interpretive processes that patients themselves engage in while experiencing and reflecting on those same side effects. Although the call for empirical bioethics continues, and in particular for in-depth qualitative and ethnographic studies of patient experience (Hedgecoe 2004; Hoffmaster 1992), with some exceptions (Bliton 1999; Bliton 2003; Churchill and Bliton, 2005; Zaner 2004), few have engaged in that work. To show the direct relevance of that kind of study, in what follows below we provide a brief excerpt from a series of interviews with PD patients.

Morrison: Is there any way in which you feel different as a person since you've had this device put in?

Amelia<sup>1</sup>: Yes. Now let me try to pin it down. Before I had the device put in, I felt as though I were disappearing. That Amelia was ceasing to exist. Hard to be more specific. . . . A friend of mine whose husband has Parkinson's said, "I want Nick back." In a sense I feel that I've come back. Not the same person. But I am a person again. And hmm . . . It's a very intangible feeling. It's definitely a positive one. I do feel that I've been handed some identity back.

...

I'm not quite, it's not handing back who I was, but it's handing back a person, an identity. A functioning identity that isn't quite what it was, but it's real.

...

Morrison: When you say "Getting identity back"?

Amelia: Hmm. Well for a while, just before I had it I, I was a person with Parkinson's. People felt sorry for me. Or they ignored me. Or they treated me like you treat someone with a neurologic disorder. And they're not doing that now. So that's what I meant by getting back. But it's more than that. It's, now it's having an identity again, even though it's not the same identity.

Morrison: So you're not the person you were before with Parkinson's. And you're not the person you were before the Parkinson's all together.

Amelia: Right. But I have more in common with the person I was before the Parkinson's than I do with the person who had Parkinson's. I think that about says it.

A retired editor, Amelia is well educated and articulate. When asked to discuss how, if at all, her sense of self has been altered by the addition of a brain stimulator to her body, she offers her narrative of a previous self disappearing, her life progressively diminishing in its breadth. Her narrative recalls who she was "before," which also contributes to her response to and interpretation of the effects of DBS. In other words, patients like Amelia often interpret the effects of DBS (including those labeled "side effects") in view of their recalled past—in her case, a declining self.

Amelia reports that her symptoms have, for the most part, been effectively treated. What then becomes most intriguing is her idea that she has come back, that some element of her "self" has returned and yet she is not the person she was prior to PD. She emerges from her implantation happy to have received the device, and feeling altered in her sense of self. In her talk about postimplantation, she says that she does not experience the pitying looks nor the inattention from others due to her PD symptoms. From her perspective postsurgery, she seems to distance her current self from the person she was before surgery, articulating a new and regained sense of self. For Amelia, the effects of the DBS have allowed her to regain a *self*, one not so intimately connected to the symptoms of PD. Amelia's new self is expressed as a functioning self in the public sphere, in contrast to her prior experience of a stigmatized identity subject to the unrelenting symptoms of PD.

Stories like Amelia's should give us pause when considering the "side effects" of DBS treatment for Parkinson's and other illnesses. Our own work with physicians and patients has convinced us that the process of receiving an implant and interpreting its effects are not nearly as straightforward as readers of Müller and Christen's (2011) article might be inclined to believe. Focusing on the "side effects" of DBS treatment for PD is indeed laudable. In our experience of speaking with and listening to patients talk about their life after DBS surgery, we find that some patients *interpret* the treatment and side effects of the DBS on a daily, sometimes hourly basis. Many also interact with the device by raising or lowering stimulation levels. Patients also report testing themselves, and the device, in a variety of home and public contexts, examining the limits of their treatment effects. Focusing on the embodied aspects of treatment experiences highlights the interpretive process that patients undertake when learning to live with, modify, tolerate, and expand the effects of the DBS device, many times differentiating these effects from continued medical therapies.

1. All names in this passage, except Morrison, are pseudonyms. This project, "Patient Experiences with Medical Devices: The Case of Deep Brain Stimulation," has received approval from the Vanderbilt University Institutional Review Board.

Müller and Christen's typological analysis may not be applicable to any particular patient's circumstances. Patient experiences of DBS treatment may not fit readily into their typology of measurement complexity and relative life impact. Furthermore, attempting to discipline a patient's understanding of his or her illness into the generality of these categories is at best premature and at worst inappropriate. The process of distinguishing benefits from side effects is indeed important and difficult. Yet at the present time these determinations need to be understood in close connection to patient experiences. In this way, patients, with their stories of illness and treatment, can help doctors and ethicists understand these more intimate dimensions of experiences after receiving DBS. As a sociologist and a philosopher engaged in clinical work, we think that careful attention to patients' attempts to give voice to experience is just as important as any typologies of side effects that may result.

We say this because the principles Müller and Christen rely upon, while unranked in the abstract, often must be balanced in the particular situation. What then justifies Müller and Christen's principlist view of bioethics in consideration of patients who report side effects with DBS for PD? As Richard Zaner (1994) suggests, it may be premature to address such grand issues as principles applied to the DBS case before we have understood, as fully as possible, the sensitive and complex issues that patients face in their struggle to determine the full range of possible futures available to them should they choose to pursue DBS.

We can conclude by suggesting that we should continue to examine more carefully, using the most sensitive qualitative and interpretive research strategies available, actual patient experiences to determine, in practice, what is most important to them. By focusing on outcomes important to patients, we become more sensitive to effects patients consider beneficial to their lives. Mathieu, Bell, and Racine's (2011) discussion of patient-reported outcome measures (PROMs) seems to support such an effort. On the other hand, standardized outcome measures like theirs are based on assumptions that the "same" concept can be used effectively to explain the experiences of different people. It would seem that their aim is to have such outcome measures quantified and standardized for PD. However,

because their assumptions risk significant distortion of patient experiences, both their assumptions and their aims need to be examined and established. Not only is there a great deal at stake in moving forward with DBS, there are likewise multiple layers of interpretation important here, and these present experiences of meaning by patients that must be explored as carefully as possible. We argue, therefore, that current research on DBS patients can be fruitfully extended and clarified by in-depth, qualitative studies of patient experiences that enhance our knowledge of significant changes in self-understanding that some people with DBS devices report. ■

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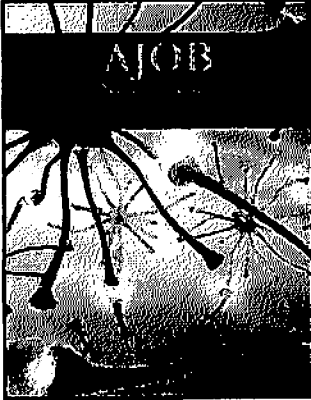
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