



HHS Public Access

Author manuscript

Camb Q Healthc Ethics. Author manuscript; available in PMC 2022 October 01.

Published in final edited form as:

Camb Q Healthc Ethics. 2021 October ; 30(4): 623–630. doi:10.1017/S0963180121000098.

Trading Vulnerabilities: Living with Parkinson’s Disease before and after Deep Brain Stimulation

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Abstract

Implanted medical devices—for example, cardiac defibrillators, deep brain stimulators, and insulin pumps—offer users the possibility of regaining some control over an increasingly unruly body, the opportunity to become part “cyborg” in service of addressing pressing health needs. We recognize the value and effectiveness of such devices, but call attention to what may be less clear to potential users—that their vulnerabilities may not entirely disappear but instead shift. We explore the kinds of shifting vulnerabilities experienced by people with Parkinson’s disease (PD) who receive therapeutic deep brain stimulators to help control their tremors and other symptoms of PD.

Keywords

Parkinson’s disease; deep brain stimulation; implanted medical devices; cyborg; vulnerability

“It does make me realize how fragile we are as human beings. And how wonderful it is that people have learned how to do something to help it along.” (#1, pre).

“I feel like I am more vulnerable right now than I was before.” (#7, post).

Implanted medical devices—for example, cardiac defibrillators, deep brain stimulators, and insulin pumps—offer users the possibility of regaining some control over an increasingly uncontrollable body, the opportunity to become part “cyborg”¹ in service of addressing pressing health needs. Most implanted devices are interventions of last resort, given surgical risks and recognition that device components can fail. Still, individuals for whom they are recommended often gladly take on those risks in hopes of achieving both symptom (reduced threat of arrhythmias, tremor, dyskinesias, gait, and immobility) and behavioral (social, avocational, employment, driving, and daily function) goals.² Feeling vulnerable in light of their bodies’ unruliness, hopeful individuals consent to surgically implanted devices.

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We recognize the value of such devices and their capacities to address symptoms of concern, but want to call attention to what may be less clear to potential users—that their vulnerabilities may not entirely disappear but instead shift. Vulnerability is a state of being fragile, or susceptible to particular kinds of harms or threats.³ Of course, no human lacks vulnerability, given our embodiment and our social and emotional dependency on others, but medical interventions are still often presented as (or thought of as) ways to “cure” a body with a troubling condition. Potential device users may feel relatively well informed about the risks of surgery and the intended benefits of the device, without fully understanding the new vulnerabilities likely to arise from even successful use of the device.⁴

Consider, for example, how Katherine Standefer, a journalist and writing instructor, describes her experience with her implanted cardiac defibrillator (ICD), which was initially set with a low threshold and shocked her unnecessarily.⁵ The shocks knocked her off her feet; she felt attacked from the inside. In the wake of the painful and debilitating shocks, she described her fear that it might happen again, and her existential uneasiness: “Now I understood there existed inside me a machine I could not control, subject to both human and mechanical errors. . . . I saw for the first time that the ICD could as easily kill me as save me. The promise of being a cyborg was hollow.”⁶ The promise she heard included the removal of vulnerabilities related to heart arrhythmias, but the reality was somewhat different, given the varieties of new threats related to the device. Unlike other devices that operate outside the body, and might be set aside or intervened upon directly by the user, implanted devices create a “continuous, inextricable intertwinement of technologies and [user] bodies.”⁷

In this paper, we explore the kinds of shifting vulnerabilities⁸ experienced by people with Parkinson’s Disease (PD) who receive therapeutic deep brain stimulators (DBS) to help control their tremors and other symptoms of PD. We draw our examples from an interview study done with PD patients ($N=22$) receiving therapeutic DBS devices.⁹ Following an approach employed by others^{10,11} participants were interviewed once prior to surgery, and again postoperatively (approximately 5 weeks after the surgery).¹² Quotations used in the text are identified by interviewee number and “pre” or “post” to clarify the timeframe.¹³ Interview questions focused on participants’ expectations and experiences regarding deep brain stimulation and agency, but a theme of vulnerability was readily apparent across transcripts analyzed independently by two readers.

Our aim in calling attention to the shifting vulnerabilities of PD patients undergoing DBS interventions is to provide a more robust picture of life with an implanted device. Presurgical informed consent discussions already focus on surgical risks (e.g., infection and bleeding) and potential recipients are likely to hear something about device risks (e.g., potential for malfunction or scarring around the electrode). In addition, we propose a closer investigation of how devices may shift vulnerabilities, to better capture what is at stake in undergoing this implanted device therapy. In making decisions about implanted device interventions, patients will benefit from having realistic expectations, not only about what they hope for in terms of symptoms relief,¹⁴ but also in respect to new challenges and susceptibilities that are likely to arise. Acknowledging the prospect of these new vulnerabilities can help to ensure the robust appreciation that is the hallmark of informed medical decisionmaking.¹⁵

The paper includes three sections: (1) identification of three common vulnerabilities experienced by people living with PD; (2) exploration of how those same vulnerability categories shift with the introduction of a DBS device; and (3) discussion of why understanding the nature of these new vulnerabilities is important for robust informed consent.

Three Vulnerabilities of Living with PD

PD is the second most common neurodegenerative disease in the world and involves progressive decline in motor function and psychological and cognitive changes.¹⁶ People who develop PD experience vulnerabilities that may be new to them, and that require adaptation. For instance, asked about their experience with PD, participants noted experiences that we grouped in three categories: stigma, lack of control, and dependency.

Stigma.

Participants noted the ways in which living with PD led to stigma, given the tell-tale signs (e.g., tremor, facial masking, and dyskinesias) of neurological issues, and other people's fear or lack of understanding:

“I think this is the nature of the disease that you are more self-conscious about your tremor and things like that. You think, ‘Everybody must be looking at me.’” (#8, pre).

“You have to be exposed to the people, and that acceptance of being exposed is the most difficult piece in that disease. Because a lot of people like myself, I did not want to come out of the house because I did not want somebody else to see my weakness. I did not want them to be sorry for me, you know?” (#7, post).

“Well, some years ago, I did a project for a retired sports celebrity, and the first time he met me... I mean I had the kinesias [dyskinesias] and the tremor. First time he met me, he thought I was an alcoholic and I almost did not get the job. ... Ever since, when I meet people, I usually tell them I've got Parkinson's Disease, it's not contagious, and it does not affect my thought processes. Yet, I've lost a number of jobs because people do not understand that.” (#10, pre).

Worry about how one is perceived, and the negative consequences of that perception, are significant issues for people with PD. Although most people adapt easily to a slight tremor, more significant pathophysiological effects fuel stigma from others, and self-protective restrictions. Given evidence that stigma is a key determinant of quality of life for people with PD,¹⁷ people who seek DBS for PD may be aiming to address the stigma related to the symptoms of the condition.

Lack of control.

Participants were frustrated with the difficulties they experienced in controlling their bodies. They felt vulnerable to blunders (even if no one else was around to stigmatize them) and were unable to participate in some of the activities they desired. These quotes demonstrate

their lack of control over how their bodies move and function, and their desire for greater control.

“I know I get frustrated when I shake, when I’m doing something on the computer, or I’m sending a text, but I know that’s the disease.” (#4, pre).

Thinking ahead to the prospect of DBS use, participants noted aims related to handling their PD-related lack of control.

“I would hope coming out of this, yeah, it [will] control the stiffness and the oddball reactions I have every once in a while. I would say just allow me to control my actions.” (#3, pre).

The expectation is that “the device gives me control ... It’s like adding power steering to a car.” (#3, pre).

Another participant, reflecting back, noted his difficulties in keeping up with his wife on trips outside, and his hopes for a significant change with the device: “I can go to the Walmart and can kind of keep up with her, not to have to stop and rest. That’d be a big deal. I could not do that before. Standing. I could not stand for too long in one place.” (#2, post).

The progressive nature of PD means that people living with the disease face increasing degrees of loss of control; that loss of control makes them vulnerable to falls, difficulty in modulating their speech, problems with swallowing, and so forth, and eager to regain more control.

Dependency.

People taking medications for PD symptoms often have strict schedules for dosing. Missing a dose can result in significant physical and/or cognitive difficulties. Reliance on medicine, and on other people to help with a variety of tasks related to activities of daily living, can result in a felt sense of dependency.

“I always get up in the morning and once I take my medicine and get moving, I get along for a certain amount of time and then all of a sudden it’s like I’m running out of gas. I just slow down and start freezing up. If I can keep that from happening, I just do not feel exhausted all the time. I just want to go back and go to sleep.” (#3, pre).

“...[T]he medication, after about three years, it became unpredictable and I kept having to take more and more so it was not effective... I actually felt the tremors with the medication; like Levodopa, if I do not take it, I cannot walk.” (#5, pre).

“I knew I had to do something, because my disease is getting worse... And when my medication was off, that’s when I ... that’s when my feet suffer, when I have to hold onto something... But when the medication is working, I’m fine. I can run, I can do whatever.” (#12, pre).

People who seek out implanted devices often hope to reduce their dependency on others or on medications. As Gardner (2013) notes, “Stories of previously housebound patients with debilitating symptoms subsequently regaining independence and self-confidence with

DBS are not uncommon, and the media has tended to portray the therapy in very optimistic terms.”¹⁸ Along similar lines, DBS manufacturers, such as Abbott, promote the therapy as one that can result in increased independence¹⁹; Gardner (2019) provides a good discussion of other online depictions of life with DBS.²⁰

New Vulnerabilities Arising from Device Use

Treating PD with DBS can help address some of those vulnerabilities, but it also brings on new ones, including the stigma of having needed surgical intervention on one’s brain and some felt uncertainty about one’s agency or degree of control and responsibility for action. It can also bring increased dependency, in respect to needing to be near physicians for adjustments, requiring electricity in order to keep the DBS functioning, and having to avoid metal detectors and other screening devices. We demonstrate these new felt vulnerabilities through the quotations below.

Stigma.

Surgical intervention can leave signs (e.g., scars) that themselves may result in stigmatized perceptions.²¹ In addition to scalp or chest scars, some DBS device users articulated issues with the bulkiness of the implanted battery pack and pulse generator, or evidence of subdermal wires connecting the pulse generator to the leads. Device users may fear being perceived as cyborgs.²²

“We live in a superficial world, so people place judgment on the person they see. That’s the first sense that they have, so they are going to see something and they’ll categorize that... I think [they may] not see me but see maybe the scars.” (#11, pre).

“[I]f they knew that I had brain surgery, they may not know what the details about that are. I mean, I feel for myself, I feel it’s [DBS’s] going to be an enhancer. But I feel that other people’s perception without knowing the details can have a negative effect.” (#11, pre).

“One thing I was concerned about is that people would look at me as a brain damaged person.” (#6, post).

“[T]here’s this thing called damaged goods ... So I think you are going into a place that we really do not understand fully, into the brain. So, I work with a bunch of engineers, so we are constantly analyzing stuff. And so I think that once you go into some areas, control system if you will, and you mess around with things you do not know about, then they think that, that perception could be, ‘Well maybe his opinion is flawed, or his judgment is flawed.’” (#11, pre).

We recognize that many people may prefer the possible stigma of having a device to the known stigma related to tremor and muscle rigidity, but believe it is nonetheless important to acknowledge that experiences of bodily stigma are not so much removed, as reoriented.

Lack of Control.

Although DBS is often highly effective at allowing PD patients to carry out simple daily activities, users of these implanted devices may face different kinds of uncertainty related to a lack of control. Some participants expressed a degree of hesitation or doubt about relative responsibility and control:

“Well, like if I trip while I’m walking or lose my balance, do I say, “Oh that’s the DBS or that’s me doing it?”” (#8, post).

“[M] wife and I were up in New York City earlier this week and we were walking through the rain to get back to Penn Station. ... we were walking and between the puddles and, feeling unsteady on my feet, I held onto my wife’s hand. All the while, I’m trying to figure out where to put my feet and I’m also trying to figure out what is causing this? ... Yeah, I’ve often thought, ‘Hm, what’s going on here? I did not mean to put my foot there. How did it get there? Why did I catch my foot on the rug?’ That kind of thing. I have had those thoughts. ... Yeah, I thought, ‘Is it the DBS? It must be. It can’t be.’” (#8, post).

“Well, it’s more the DBS more than anything, I mean, you know, ... Say ‘Listen, Doc, I need you to, you know, adjust me again or whatever.’ You know what I mean? But, yeah, yeah, I would say more or less the DBS is more in control of me now, you know.... I mean, it’s not gonna tell me, you know, ‘Okay, you know, murder this guy or get that guy.’ You know what I mean? Because I do not think you could do that.” (#19, post).

What has been called “ambiguous” agency²³ in previous work on psychiatric DBS can similarly arise in this context: users of implanted brain devices may “lose track of their sense of agency if it became unclear whether they or the device was responsible for their feeling or acting in a certain way.”²⁴

Dependency.

Because DBS may allow a reduction in medications in some cases, patients may hope for less reliance on the specific timing of dosing.²⁹ In most therapeutically approved devices, stimulation is constant, or can be turned off at night, but does not require regular readjustments during the course of the day. Because the stimulation helps to reduce symptoms of PD (e.g., tremors and rigidity), DBS users may also gain independence in respect to carrying out activities of daily living (e.g., eating, dressing, and shaving). Yet DBS recipients also expressed concerns about their new dependency on electricity, on physicians or others for adjustments, and upkeep of the device.

“God forbid, there’s no electricity in the city, how am I going to recharge my battery? In that terms, you know? I have to think twice before doing something which I was doing before without even thinking. So I have to think in advance.” (#7, post).

“It’s something that from what I understand, I’m going to have to charge every night. I’m going to need to see the doctors at certain times to have them adjust it.” (#13, pre).

“I have to watch ... No going through metal detectors. If I need an MRI done, I have to come to University of XXX from now on. So, that’s affecting what I do ... If I had the operation tomorrow, and in two months or so, am I going to be the same way that my hands will be good, my walking will be good, or will I find that I would, at times, go back to where I’d have problems with writing, problems with doing something, and then I need to go back in to have ... I guess you ought to call it a tune-up. So, it’s almost like I’m going to be like a car.” (#13, pre).

“[T]he first time when I fly, then. Do they have to check me out? You know, do I let them know I have a [brain] pacemaker?” (#16, post).

Although people with PD may be interested in DBS in order to regain or improve their independence, they also face a different kind of dependence in using the device. Dependence, of course, is not necessarily something to be avoided; many feminist and disability scholars have compellingly articulated arguments regarding our inevitable interdependence.²⁵ What is at stake instead is helping individuals understand the ways that their choices about available medical interventions may shift *how* they are dependent and on whom. An improvement in independence overall may still be accompanied by new forms of dependence.

Why This Matters for Better Informed Consent

Understanding the relevant risks of an implanted medical intervention like DBS is essential to ensuring autonomy in patient decisionmaking.²⁶ Patients receiving DBS for PD are informed about risks directly related to the surgery (infection and bleeding) or to potential device difficulties (malfunction, shifting wire leads, etc.). Attention has also been given to concerns about potential difficulties in understanding, appreciating, and retaining complicated medical information for people with a progressive neurological disorder like PD,²⁷ although we recognize dangers in labeling particular patient groups as “vulnerable”²⁸. To the best of our knowledge, relatively few DBS consent forms or processes include robust discussions regarding what are sometimes called psychosocial side effects,²⁹ although presurgical screening for personality or psychiatric conditions has become more common.³⁰

In our view, thoughtful and reflective discussions about how living with a DBS device not only can help with some symptoms and difficulties, but also create new vulnerabilities seem important for ensuring good decisionmaking. Some evidence suggests that thorough and critical investigations of patient (and family) goals for DBS intervention preoperatively not only can help to temper unrealistic expectations, but also leads to greater patient satisfaction.³¹ We applaud such interactive discussions prior to surgery, and recommend adding even more content. We suggest attention not only to setting realistic expectations for what the devices themselves can legitimately do (and not do) or how those advances may contribute positively to patient quality of life, but also to some of the new vulnerabilities that are likely to arise, and will require adaptation and coping.³²

Conclusion

We recognize that most recipients of DBS for PD experience some unwanted side effects or unwanted new symptoms postsurgery, but nonetheless have an overall positive response to the treatment.³³ Our aim is to highlight the importance of ensuring that individuals considering implanted medical interventions such as DBS are made aware not only of unwanted side effects, but also of new vulnerabilities created, even in the case of well-functioning devices. Living with a device is not merely about the immediate effects of the device on tremor, gait, speech, and so forth, but also about coming to terms with a different kind of stigma, lack of control, and dependency. Although none of us can escape vulnerability entirely, “we want better ways of being-vulnerable, better ways of being-at-risk. We have to learn the art and craft of vulnerability coping.”³⁴ Robust information about life with an implanted device will help people to be informed in their vulnerability trading.

Acknowledgments.

Interviews for this study were supported by the National Institutes of Health (NIH) and National Institute of Neurological Disorders and Stroke (NINDS) via grant number U01NS103799. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. We would also like to thank Rebekah Choi for research assistance, and the University of Washington Neuroethics Research Group for their feedback on the project.

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