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## Bringing Care and Maintenance Under the Same Skin: Deep Brain Stimulation and Temporalities of Care

*Aménager soin et maintenance sous la même peau : stimulation cérébrale profonde et temporalités du soin*

Marilena Pateraki

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## **Bringing Care and Maintenance Under the Same Skin: Deep Brain Stimulation and Temporalities of Care**

Marilena Pateraki

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**Abstract** — By following a posthumanist and Science, Technology and Society approach, this study analyzes technological care in deep brain stimulation for Parkinson's disease. The results are based on a survey of implanted patients with PD in Greece. I stress that, in implantation, the issue of functionality is paramount, but it also involves a “dance of agency”, an interplay of actors and actants, while the “liveness” of the technological parts imposes temporal and spatial constraints. I distinguish and analyze three modes of technological care that I encountered in the field, related to tuning, maintaining and disentangling the cyborg bodymind. I argue, finally, that these practices expand the territory of care, blurring its boundaries with maintenance.

**Résumé** — *Aménager soin et maintenance sous la même peau : stimulation cérébrale profonde et temporalités du soin* — *En suivant une approche posthumaniste et ancrée en Science, Technologie, Société, cet article analyse le soin technologique dans la stimulation cérébrale profonde pour la maladie de Parkinson. Il est basé sur une enquête menée en Grèce auprès de personnes implantées atteintes de la maladie de Parkinson. Je souligne que, dans l'implantation, la question de la fonctionnalité est primordiale, mais qu'elle implique également une « danse de l'agentivité », un jeu d'acteurs et d'actants, ou la « vivacité » des éléments technologiques impose des contraintes temporelles et spatiales. Je distingue et analyse trois modes du soin technologique que j'ai rencontrés sur le terrain, et qui sont liés au réglage, à l'entretien et au démêlage du corps-esprit cyborg. Je soutiens, enfin, que ces pratiques élargissent le territoire du soin, en brouillant les frontières avec l'entretien.*

Mots-clés : sciences/techniques et sociétés, anthropologie et ethnologie, éthique, médecine et santé, techniques et technologies, stimulation cérébrale profonde (SCP), soin technologique, danse de l'agentivité, entretien, temporalités, époque contemporaine

THIS study focuses on technological caring in Parkinson's disease (PD) patients implanted with Deep Brain Stimulation (DBS). DBS, a core neuromodulation technology (STOA, 2012), is implemented as a treatment in PD, drastically reducing many symptoms, and restoring the patients' functionality.

However, the result of implantation is a "cyborg" (Haraway, 1991), a combination of human and machine; and as the device intervenes in the brain, DBS has raised ethical concerns. But, while a number of studies have focused on the putative effects of DBS on patients' personality, identity, agency, authenticity, autonomy and self (PIAAAS), relatively little attention has been given to the caring practices accompanying DBS implantation, despite some notable exceptions (Gardner, 2017; Gilbert & al., 2017; Lancelot, 2019; Moutaud, 2011). Adding to that, the scarcity of first-hand studies on this crucial matter spurred my interest. Examining the experiences and the tradeoffs of cyborgization, I conducted field research in Greece from 2016 to 2018.

In this contribution, I will focus on technological caring, in which human and material agency enmesh in chronic illness. Following an STS and posthumanist approach, I consider it as involving a "dance of agency" (Pickering, 1995; Oudshoorn, 2015; Dalibert, 2022). Thus, I contemplate the cyborg bodymind as the site of the enactment of a dialectic of resistance and accommodation between PD, DBS, medication, and the environment. I also argue that, in examining caring in DBS, one should take into account the "liveliness" of technological parts (Bennett, 2010).

Thus, I will proceed in three steps. In the first part, I will initially explain the working principles of DBS in PD, then my research, and finally I will lay down my conceptual framework. In the second part, starting with the "bodily doubt" (Carel, 2016) experienced by PD patients, I will showcase the importance of functionality as the desirable outcome of DBS. But functionality is not a stable state in implanted patients, as cyborgization involves caring fluctuations which I link to process time (Reinecke & Ansari, 2016; Davies, 1994). In the third part, then, I will distinguish and analyze the three types of technological caring practices that I encountered in the field as tuning, maintaining and disentangling the cyborg bodymind. Part and parcel of every implanted person's life, these practices are heterogeneous, as they are linked

in different ways to the under the skin device. But, despite their differences, all three are related to the “liveliness” of the technology, and all of them are enactments of networks in which the cyborg bodymind finds itself entangled (Hodder, 2012). I will argue, finally, that these practices expand the territory of care, blurring its boundaries with maintenance.

## **1. Mapping the Terrain of the Research**

Starting with a presentation of the device, I briefly explain the working principles of DBS technology in PD. I turn subsequently to the specifics of my field research. After presenting the sample, the process, the ethics of my research, and the method of analysis of the results, I turn to the issue of agency in DBS, as discussed in neuroethics, before laying down my conceptual framework.

### **1.1. Deep Brain Stimulation and Parkinson’s Disease**

DBS involves a surgical procedure that consists of the implantation “under the skin” of the following elements: firstly, a pulse generator (IPG), or the neurostimulator or, as many patients call it –the battery. IPG houses the battery and the electronic components regulating the stimulation parameters. Secondly, DBS involves one or two leads placed in the skull which target specific brain areas with electrodes. Thirdly, there is a lead extender that connects each lead to the IPG. The electrodes are implanted into the precise brain locations that generate the abnormal signals which give rise to the symptoms. Finally, the last part of the system are burr-hole caps that fix the position of leads (Eljamer, 2013, p. 20). The system is controlled by two external devices: a physician’s programmer regulating the stimulation settings (voltage, pulse width and polarity of the pulses), and a patient’s controller to switch the IPGs on/off, increasing or decreasing the level of stimulation, and checking the battery level (p. 22).

In PD patients, IPG transmits a high-frequency electric discharge 130-185 Hz, with pulses of short duration between 60-100  $\mu$ s, and 1-3 mA in amplitude, into particular structures deep in the brain (Garcia & al., 2005). This high frequency stimulation, changing brain activity, alters the abnormal signals caused by PD, leading to an easing of the symptoms. Electrode placement in PD patients targets the specific brain structures related to motion. Although the exact mechanism of the action of electricity in the brain is

unknown, it is believed that DBS works by dissociating input and output signals, “disrupting the abnormal information flow through the stimulation site.” (Chiken & Nambou, 2016, p. 314)

The most common implementation of DBS is in people with PD, a chronic neurodegenerative disease. Due to a “progressive degeneration of the dopaminergic neurons of the ventral midbrain” (Rao, 2007), PD is accompanied by motor (akinesia, bradykinesia, tremor, gait disturbance, etc.) and nonmotor (dementia, depression, cognitive impairment, hallucinations etc.) symptoms. Although DBS does not halt the progression of PD, it frequently reduces certain of its symptoms, especially tremors and rigidity. DBS is generally combined with oral medication, while its implementation is not considered a suitable method for all PD patients.<sup>1</sup>

As an under the skin implanted system, DBS is the materialization of a cyborg relation (Verbeek, 2011, p. 151). In order to capture the experience of cyborgization in chronic illness I conducted empirical research.

## 1.2. Research Methodology

My data was collected for the requirements of my PhD research at the National Kapodistrian University of Athens. In order to examine cyborgization in chronic illness, I planned and conducted qualitative field research that I undertook from September 2016 to December 2018. My empirical material consists of 45 interviews: 19 with PD patients, all implanted in Greece (Attica and the Peloponnese); 13 with caregivers (relatives and professionals); 5 with activists with PD but not implanted with DBS (Central Macedonia); and 8 with health professionals (Attica and Epirus). I met the implanted interviewees with the assistance of two neurologists working in two major public hospitals in Attica. Two friends helped me to come into contact with four other implanted patients. I conducted the interviews in the patients’ homes, in hospital rooms, in medical offices, in coffee shops and in the Offices of the Patients’ Association in Central Macedonia, while two patients were interviewed over the phone. The ratio of men to women was almost 1:1 among the patients and caregivers, but among health professionals I spoke to only two

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<sup>1</sup> The patient selection criteria rely on an outdated paper of 1999, the Core Assessment Program for Surgical Intervention Therapies in Parkinson’s Disease (CAPSIT-PD), and vary across neurologists (Artusi et al., 2020).

women. Following grounded theory and situational analysis methods, I conducted semi-structured, in-depth interviews, lasting from thirty minutes to two hours (Strauss & Corbin, 1990; Charmaz, 2006; Bryant, 2017; Clark, 2005). The discussions were recorded and then transcribed verbatim. Furthermore, I kept observational notes with which I balanced the discursive data.

My research took place before the EU General Regulation for Data Protection (GRDP) acquired the status of national law in Greece (with the law 4624/2019). However, under the guidance of my supervisor, I followed strict ethical guidelines, in conformity with the principles of the GRDP. In the absence of a regulatory framework for interviewing, the interviews I conducted in two public hospitals were based on the consent of the treating neurologists, and of the patients themselves.

I also obtained the consent of all the interviewees for the use of the data for research purposes, and I explained my research to them succinctly. I used pseudonyms in order to preserve their anonymity. All the interviews were conducted in Greek. While some of my interviewees faced speech impediments, and others manifested signs of cognitive decline, I intended from the beginning to include them in my research. Despite the difficulties I faced in transcribing the interviews, it was crucial for me to have the most diversified sample possible.

From my first interviews, I started transcribing and reading my material again and again. After the completion of the survey, I created a unified document including my observational notes. I read the material over and over again, until I was able to stabilize the thematic clusters.

During the elaboration of my data, I became aware of the existence of several temporalities at play, woven into experiences of sociotechnical arrangements and everyday practices of the DBS implanted patients. The emergent importance of caring practices in DBS demonstrated to me that implantation is a dynamic process, which is context- and time-dependent. Furthermore, this care is crucial in restoring and maintaining the agency of the implanted patient. This reference to the patients' agency in DBS, needs some clarification.

### 1.3. The Issue of Agency in DBS

I met Antonia twice; in a café and then at home, where she invited me. Very hospitable and affable, the 56-year-old former saleswoman was diagnosed at 39, and implanted with DBS 9 years later. Now, having 8 years of experience in cyborgization, she explains:

After DBS, I expected to be like I was before, to be well. I took this for granted. [...] Well, it takes a constant effort to be well. Initially, access [to DBS] was delayed, and [afterwards] the implantation and its sequels were very painful. Furthermore, it [DBS] requires calibration, which adapts the device to my body, changes in medication, battery replacement [IPG], and I have to be careful as to where I am in order to avoid accidents. In other words, living with DBS is not so simple. (Interview with Antonia)

This narrative highlights key issues for my analysis. Firstly, Antonia voices her initial expectations, the certainty that after DBS implantation, she would “be like before.” Secondly, she speaks as a longtime implanted person, knowing the vagaries of cyborgization well. She explains that “it takes constant effort to be well” pointing directly to the fact that DBS implantation is not one-way process, a “technological fix.” Thirdly, she points to some practices that are directly related to her caring.

Although I was expecting to find evidence related to PIAAS changes in patients with DBS, most testimonies seem to point elsewhere. The “effort” Antonia –and many others– mentioned, concerns on the one hand the restoration of agency, that is, of functionality, while on the other it is linked to some practices related to care. The focus on PIAAS changes, as the “alteration of the self” (Ford, 2006) thus seems to occlude significant aspects of the cyborg experience in chronic illness. This focus, furthermore, only on the possible mental or sentimental effects of DBS, disregarding the bodily aspects of cyborgization, is tainted with neuroessentialism, the belief that the brain defines who we are (Gaillard, 2018, p. 40).

Thus, following an STS and posthumanist perspective, I examine the episodes mentioned by Antonia, such as “calibration”, or “battery issues” etc., as moments of a “mangle of practice”, with “human and material agency reciprocally and emergently intertwined” (Pickering, 1995, p. 21). As in Pickering, this mangle involves a “dance of agency”, a constant interplay between the patient, the device and the sociotechnical environment (Pickering, 1995;



Oudshoorn, 2015). This “dance” is, firstly, the instantiation of a dialectic of resistance and accommodation, where the advancing PD is seen as resistance, while the constant adaptations of the stimulation is seen as accommodation.

In this “dance” the mind-body dualism has no particular role to play. That is why, in order not to separate the mental and bodily effects of DBS, I adopt the term the “bodymind”. “Bodymind”, a concept coined by Margaret Price, originates in materialist feminist disability studies. For Price (2015, p. 269), mind-body dualism makes no sense: since mental and physical processes interact, are intertwined, and act jointly, they should be understood as one. This stance is consistent with a philosophy of care that, according to Xavier Guchet (2021, p. xxiii), refuses “any form of a split between the body and the spirit.”

Furthermore, by conceiving agency in DBS as distributed, I focus on the bodymind’s interplay with other actants, provided with thing-power. Acknowledging that, in DBS, “nonhuman materialities have power” (Bennett, 2010, p. 16), I wanted to stress the dynamics of stimulation, such as the “liveliness” of the electricity flowing through the bodymind. Thus, by focusing on the process of the interactive stabilization between its components, I will show that agency in cyborgs can be seen as the result of a “mangle of practice” between actors and actants, human and material agents involved in the DBS caring functions.

Finally, I see the implanted bodymind not as individualized, but as entangled, caught in a web of dependencies allowing empowerment. Drawing from Ian Hodder’s entanglement theory, I describe the links that allow the workings of the cyborg, to the wider sociotechnical system as “entanglement”, as a heterogeneous mixture of human and things, “culture and matter, society and technology.” (Hodder, 2012, p. 208)

## **2. Functionality, Caring Fluctuations, and Process Time in Implanted Bodyminds**

In this section, I will unfold the aims and the temporalities of caring in chronic illness. I argue that, as long as DBS does not “cure” PD, and does not eliminate impairment, it remains a method of “caring”. Its action is restorative, as it relieves symptoms and partly restores functionality, without eradicating the causes. Thus, I initially explore functionality, relieving the “bodily doubt” experienced by PD patients. Then, I show that caring for

implanted bodyminds is tailored and relational, adapted to the fluctuations of the symptoms, and the stages of the illness. Finally, I link these fluctuations to “process time” induced by implantation.

### 2.1. Bodily Doubt and Functionality: The Empowering Effects of DBS

During the process of interviewing, a salient feature emerged, a feeling of uncertainty which was common to all my respondents with PD. I met Zoe, a 46-year-old former IT engineer, in a public hospital. She was diagnosed with PD at 40, and three years later she was implanted. I spoke to her while she was attending her calibration session, a procedure that all DBS patients have to undergo every six months. Describing her experience with PD she explained to me:

This illness is sneaky. [...] You don't know what will happen to you the next day, or even the next moment. As it progresses, you don't know what else to expect. I reached the point of not recognizing my body anymore; its reactions [symptoms] were unpredictable. I felt –and I still feel– uncertainty. (Interview with Zoe)

For Zoe, PD appears as a “sneaky” actant, intervening at any time, disturbing her habits. Furthermore, as it progresses, she feels all the more distanced from her “known” body, a situation causing her uncertainty. As similar testimonies started accumulating, I subsumed them under the category of “bodily doubt”, using a concept coined by Havi Carel (2016). The concept encompasses key aspects of this uncertainty, encapsulating the experience of living with a chronic illness and disability. “Bodily doubt” is conceived as the opposite of Maurice Merleau-Ponty’s “bodily certainty”, a certainty anchored in the “habitual body”, the one that performs most of our everyday gestures in a non-reflexive way (Merleau Ponty, 1945). Occuring at any moment, invading the normal sense of things and revealing our vulnerability, bodily doubt leaves also a permanent mark on the patient (Carel, 2016, p. 93-94).

Relief from many of these “bodily doubts” is the outcome of a successful DBS procedure, as the patients are getting back at least some of their former functionality. Functionality is the desirable outcome of DBS. Adam explained: “Functional means to be able to do whatever everyone else does.

To tie my shoelaces, to put on my shirt, to button it up, things I couldn't do before. That is, I had a hard time doing them.” (Interview with Adam)

Adam, eleven months into DBS, seems satisfied with the outcome. The 54-year-old former bank clerk was diagnosed with PD almost eleven years before his implantation. He has since then seen his life change. As freezing stopped, his former functionality was restored; this affects his everyday activities, his tempo, and rhythms. In Nikos' testimony, the cultural component of the dance of agency of DBS appears: the social framework, the aim of DBS is functionality. After a successful tuning, the components in his treatment are aligned, and he can actively shape his everyday life.

Facing Zoe, with her DBS off and without medication, barely able to speak in a low and exhausted voice, I got an idea of what the interruption of stimulation entails. Beside her was Yannis, her husband and occasional caregiver, who did most of the talking. He praised DBS to me, insisting that it had “resurrected” his wife: “Before implantation she was unable to do anything [...], either to lie down, or to get up, or to eat, or to go to the toilet, or to get dressed, or to do anything.” (Interview with Yannis) The disease is portrayed as a sort of “death”, a death that refers to the vulnerability due to cyborgization. When DBS worked, Zoe's mobility was vastly improved: “Before DBS, she had OFF periods at hourly intervals, now it's once a day.” (Interview with Yannis)

But when I met Adam, his stimulation was working while in Zoe's case it was not. Since the technology, the actants under her skin –DBS and medication– were temporarily on hold during the process of calibration, she was experiencing rebound effects, meaning the return of intense symptoms. Calibration then, can be considered a form of tuning, “a kind of delicate material positioning” (Pickering, 1995, p. 14), or of the interactive stabilization of human and material agency (Gasparre & Tirabeni, 2023, p. 5; Oudshoorn, 2015). This procedure, that I will discuss further in section 3.1., is a routine process for all implanted patients, a standard feature of the technological caring DBS provides. Thus, functionality is not a stable state in implanted patients, while caring fluctuates over time.

## 2.2. Caring Fluctuations and Process Time

As a neurodegenerative condition, PD symptoms are progressive and variable for each patient. Technologies such as medication and DBS,

generally reduce symptoms, but eventually, as the disease progresses, the effectiveness of medication and DBS decline. Furthermore, as implanted people tend to live longer with PD, new “iatrogenic” symptoms of the disease do appear (Gilbert & Lancelot, 2020). Over time, long-term PD patients, even those with DBS, see their capacities diminish. Caring, as an ongoing process, constantly has to attune to the actants involved, accommodating medication and the level of the stimulation to the growing resistance of the illness.

Thalia knows a lot about caring practices in PD. I met her when I visited her mother Valia, at their house in Attica. The interview took place in her mother’s bedroom. Even with her DBS functioning, Valia, at 73, was bedridden and spoke with difficulty, in a low tone, and was barely understandable. She was diagnosed with PD 23 years ago, and implanted 8 years ago. Thalia, at 52, has attended to her mother’s needs all these years, as the PD progressed. She explains that:

Caring is a difficult process, because you are responsible for the other person. You always have to be on your toes. [...] I have seen my mother in various stages [of the disease], and depending on her condition each time, I adapted my assistance. Sometimes it’s simple, other times it’s not. (Interview with Thalia, Valia’s daughter)

Thalia’s caregiving fluctuated considerably over the years. As Valia’s disease advanced, she had to increasingly take on the caregiver’s tasks, helping her mother with her daily activities. Then, with DBS, while her mother regained some of her functionality, the burden of this role was alleviated. While her mother’s attunement lasted, for five years, her functionality was restored. Then, as one actant, PD increased its resistance beyond the possibility of accommodation, the effects of stimulation were lost. Thus, Thalia lies in bed, as the agency of PD has taken over.

This situation alerts us to the temporal structure of care in chronic illness. Implantation is not a one-way-process, a technological “fix”, restoring functionality. As the patient is both caught in a dance of agency between its active components and depends on wider systems of caring, the sociotechnical infrastructure which supports implantation, the argument of patients’ autonomy must at least be limited. Thus, technological caring in this case involves the continuation of a larger body of work over time, including several recurring practices, and involving a degree of tinkering. As Annemarie

Mol (2008, p. 22) clearly states, care is an open-ended process, full of unpredictability, especially in chronic illnesses: “Try, adjust, try again. In dealing with a disease that is chronic, the care process is chronic, too.”

Restoration of functionality has a temporal dimension as it means the drastic reduction of the delays and “freezings”. Adam recalls that, before his implantation, he had to plan for his delays: “Let’s say that if I had to leave the house at 10, I would start to get dressed at 9, in order to leave at 10. Because I knew that as I started to button up, I would get stuck. I experienced ‘freezing’, as they say. And DBS has changed that.” (Interview with Adam)

But as we saw with Antonia and Zoe, DBS also imposes its own temporalities. Thus, the implanted patient experiences a series of caring fluctuations, each one imposing its distinct temporality. Chronically ill implanted patients still experience good and bad days (Charmaz, 1991). After their implantation, they must abide by the necessities of cyborgization. And, besides that, they have to maintain the tempo of the dance of agency between the various actants involved in their caring on a daily basis. As Antonia told me, in order to go out, she must wait: “I can also go to a café, see some people, stroll around. Of course, that’s possible only when my medication takes effect. I receive medication, I wait for it to take effect and then I’m on the go!” (Interview with Antonia)

Here, the final outcome of the action, going out, is conditioned by the temporality of the medication. I coded these temporalities as instances of “process time”. Contrary to clock time, process time does not refer to a linear continuum, but to a time made up of interruptions, a time of processes, not of objects (Reinecke & Ansari, 2016). This time in caring is earmarked “by the capacity to take the needs and reality of the care-receiver into account.” (Davies, 1994, p. 279)

But as the temporalities of the implanted bodymind unfold, the ones related to technological care stand out. Focusing on caring fluctuations induced by technology, the “effort” Antonia mentioned, I distinguish three types of caring around DBS, tuning, maintaining and disentangling, which I will detail in the next section.

### **3. Caring for the Implanted Bodyminds: Tuning, Maintaining, Disentangling**

After implantation, PD patients’ mobility is partly restored, but, as

tradeoffs, new vulnerabilities also emerge: DBS needs periodical calibrations and maintenance, while it can, like any technology, malfunction. These vulnerabilities, as I argue, can be linked to care, while they can also be understood as maintenance. I try to categorize the instances in which these should be linked to types of technological caring. This caring is related to calibration, battery issues and “disentanglement” work, which I will examine in the next three sections.

### 3.1. Calibration as a “Dance of Agency”: Attuning the Biological and Technological

After the implantation, when the DBS is put in place, a follow-up process begins. A crucial step and a recurrent feature of living with implants in chronic illness is the process of calibration, in which the device must first be adapted and then constantly re-adapted to the particularities of each patient. One leading neurologist in Athens explained the process of calibration to me in these terms:

Once I have operated on a patient, I keep him in the hospital for two weeks, perhaps ten days. Because each electrode has four poles [...] I have to map every pole, to find the most suitable one, and then once I choose the best one, I calibrate it [the device]. [...] In three months, he is completely calibrated and then we check him every six months. (Interview with Dr. X, neurologist)

This “checking”, as in the case of Zoe, is an iterative and time-consuming process, that takes its toll on patients with DBS. For Nikos, a 53-year-old former municipal employee, implanted for almost three years, the process of calibration always seems painful. Without regretting his implantation, which he considers a “blessing”, he described his experience to me: “For fourteen days I was without stimulation and medication most of the time, so that the [the neurologist] could calibrate me, could map my brain, and this was very distressing. I saw myself as completely impotent and unable to do anything.” (Interview with Nikos)

This process might be considered as “tuning”, harmonizing stimulation and symptoms. Instantiated in a complicated setting, at the hospital, this procedure allows the various actants and actors involved to become aligned. Described as “a balancing act between the device, the patient’s activities and the battery” (Oudshoorn, 2020, p. 79), this fine-tuning initially requires the

full emergence of the agency of PD. While during this time symptoms return, a potentially successful incorporation is temporarily lost. But this is necessary, in order to accommodate the settings of the stimulation to the resistance of PD.

This can be conceptualized, then, as an instantiation of the “mangle of practice” introduced by Andrew Pickering, a constant dialectic, where resistance is the advancing chronic illness and accommodation the adaptation of the stimulation. Reverting to a language stressing practice (as in Pickering, 1995), helps us avoid the essentializing issues of PIAAAS, while concentrating on the experience of cyborgization, and specifically in the caring practices involved in DBS implantation.

Calibration can thus be considered a crucial part of the “dance of agency” of DBS (as in Pickering, 1995, p. 21), where symptoms need to be monitored in order to adjust the levels of stimulation and medication. One should not underestimate the importance of calibration. A neurologist, Dr. X attributed the perceived failures of some implantations to inadequate calibrations. Claiming that he personally had successfully recalibrated such patients, he stressed the importance of this process.

I have come to understand that in most of the cases that didn't go well, this was because they had not been calibrated properly. For instance, I have a case that for two years wasn't going well at all, she was in a wheelchair; I recalibrated her and now I have a photograph of her dancing at her son's wedding. Thus, some of those who responded unsuccessfully, did so because they weren't calibrated properly. (Interview with Dr X., neurologist)

Thus, the role of the human work of both experts and patients should not be underestimated in technological caring, while its specificity lies in the long term of its implementation (Dalibert, 2016, 2022). But this procedure involves also a degree of experimentation, and the outcomes can be surprising, as Nikos explained.

[My neurologist] was opening and shutting poles in order to test which ones would be most beneficial for me, for my facial expressions, for walking, talking, and motion. For two weeks we struggled for 4 to 5 hours a day, sometimes even for 7. And two days before the end of my hospitalization, he opened one pole in the morning without telling me, so I would be not self-suggested. He told me: I have shut down the device, and I'm leaving now.

And the device was on in a precise pole; he did such things daily, in order to fool me, to see how my body would function, if it would react to the neurostimulation. (Interview with Nikos)

When the neurologist refrained from telling Nikos the truth about the settings of his stimulation, “fooling him”, his goal was in fact an attempt to capture the agency of illness. Fine-tuning in DBS, is a complex endeavour that requires close collaboration between the implanted person and the programming physician, as in Spinal Cord Stimulation (SCS) studied by Lucie Dalibert (2016, 2022). But then a routine calibration ended up turning Nikos inadvertently into what Baptiste Moutaud (2011) has called an “experimental body”, bridging neurology and psychiatry. This instantiation shows how the entanglements between the various actants involved in stimulation can produce unexpected outcomes. Nikos’s calibration session caused a psychiatric condition, a bipolar disorder crisis:

I had a bipolar disorder crisis. [...] The doctor told me ‘In setting 3 you were crying, in 1 you were laughing, in 1.5 - 2 you were both crying and laughing’ I was laughing, crying and having suicidal tendencies. And he told me ‘I have never seen anything like this before, and I have calibrated about 1000 persons.’ They [the medical team] wanted to write a psychiatric report about it. (Interview with Nikos)

This outcome was rare and not anticipated. The result emerged as the tuning of the patient inadvertently instantiated an “experimental body”, through the production of psychiatric symptoms with the modulation of the activity of the brain structures (Moutaud, 2011). But while validating the PIAAAS changes argument, as the influence of DBS on personality is clearly demonstrated, this occurrence also informs us about the variability of temporalities in caring. Caring in DBS includes continuities but also outbursts, and concerns the entire bodymind, as mental and bodily issues are at an interplay. Thus, caring in DBS has an experimental dimension, while it can produce temporally variable outcomes.

Finally, patients themselves can perform minor adjustments. This direct interference with the device is made possible by the external controller. Not all neurologists and neurosurgeons I interviewed allow their patients, or their relatives, to handle the device. But all of them allow them to control the



on/off function in order to avoid electromagnetic interferences (EMIs) (see below 3.3.), and to monitor the power level of their battery. As Dr. X explained to me:

I never allow my patients to do it [to handle the controller]! Because DBS, specifically for PD, is done in a very small area [of the brain], which controls emotion, thought and motion. If the patient abuses it, and raises the volume too high, it's possible for him to stimulate an area responsible for emotion, and to have suicidal tendencies. So, for safety reasons I don't allow any patient to play with DBS. (Interview Dr. X, neurologist)

According to Dr. X, "emotion, thought and motion" are all connected in the intricate mechanisms of the brain that DBS affects, with no dualisms here separating the bodymind. Achilles, a 72-year-old former construction worker, had been implanted for 10 years when I met him in his luxurious apartment in the Peloponnese. Before his second battery replacement, he tinkered a lot with his DBS using the external controller. When I asked him why, he told me that he wanted to alleviate or eliminate some symptoms:

Why did I do it? You see, I am a fan of technology and I like to use the external controller and to play with the settings. I needed to do so, in order to feel and look better. What could I do since every day when you wake up, you have different symptoms? It was a way to better adapt the machine to my body. What should I have done? Since the symptoms change? (Interview with Achilles)

Achilles' playing with the device was terminated abruptly. After having relatively quickly exhausted his two first IPG's, his new neurologist forbade him from interfering with the device. As he also faces battery issues (see below 3.2.), his DBS is now improperly attuned, and his functionality has fallen drastically.

But other patients use the device with moderation, in close collaboration with their neurologists. For Nassia, a 55-year-old former lawyer, adjusting the stimulation at home has become a standard practice:

When we needed to increase or reduce the settings on the stimulator, the neurosurgeon showed us how it works. Let's say we'd increase it by 0.05, to make it easier for ourselves, because it's not possible to go to the doctor for

calibration that frequently. So, he gave us as an instruction to raise it or to reduce it a little every 2-3 days. (Interview with Nassia)

Thus, calibration involves a series of temporally distinct caring processes. These include: the work of the neurologists to achieve a successful dance of agency; fine-tuning in the sessions at the hospital between the stimulation, the disease, and the medication; and work by the patients themselves in the sessions and at home. Furthermore, all this work is dependent on the “liveliness” of the system, which relies on the electricity flowing out of the IPG. And this leads us to the two other forms of technological caring I want to showcase in the two concluding sections.

### 3.2. The Liveliness of DBS: Bringing Care and Maintenance Under the Same Skin

The second type of technological caring I encountered concerns the “life” of the under the skin technology. Sometimes, patients experience the “liveliness” of electricity directly. Martha, a 61-year-old former public servant, having already changed two batteries, described this feeling to me:

Many times, I feel the neurostimulator in my body. It pulsates, electrical current flowing within it, and I feel that it is alive, a living thing! A living thing, adding its small contribution to allow me to be well. I understood this even more when it stopped functioning. There was [pausing] how can I say it? Something inert inside me. Something dead inside me. Yes, like a dead thing inside me. (Interview with Martha)

Martha is clearly acknowledging the agency of electricity under her skin, perceiving its liveliness (Bennett, 2010). Sensing its workings, she acknowledges that this nonhuman vitality is “adding its small contribution” to her care. Finally, she laments the depletion of her battery, likening it to “death”, as it is immediately, internally, sensed.

Thus, the lifespan of the battery (IPG) defines a temporality crucial to stimulation. As Achilles explained to me: “without the battery you cannot do anything. DBS doesn’t work, and you feel terrible. Just before the battery powers down, they have to care for it and replace it.” (Interview with Achilles) When the battery is depleted, stimulation stops and the device is idle.

Here the “liveliness” of DBS is acknowledged immediately by its bodily effects. Achilles had the experience of losing his agentic power for a long time. And when he says that “they have to care for it” he addresses a reproach to a system that failed him, a system in which DBS is entangled. It is in Achilles’s testimony then, that the third component of the “mangle of practice” appears –the agency of the existing culture (Gasparre & Tirabeni, 2022, p. 2). According to Achilles, “they” are his healthcare providers, the Greek National Healthcare System (ESY), and its administrators.

This case of battery depletion showcases the dependency of caring technologies on the wider sociotechnical infrastructures upon which they depend for their smooth functioning. Achilles had to wait over a year for his third battery to come, due to healthcare cutbacks. All this time, his symptoms returned, and even worsened. When I met him, his device was at a very low setting, in order to prolong the lifespan of its battery. As I documented, in most cases, this belated replacement causes serious issues for implanted patients. The battery, having completed its life cycle, is finished, crippling the implanted bodymind. And this implies long periods of waiting. Martha had to wait for a whole year in order to have her battery replaced, as her operation was constantly postponed for financial reasons.

Look, the first battery was depleted three years ago [in 2014]. The hospital administrator would not agree to enter into this process [of the approval of the surgery], that is to authorize the payment of this sum. Changing the neurostimulator costs a lot of money. [...] It was in the midst of the [financial] crisis, and all hell had broken loose. (Interview with Martha).

In this case, the infrastructure behind DBS, the entanglements upon which the implanted bodymind depends, become visible. As Susan Leigh Star (1999, p. 382) points out, infrastructures become visible only when they are breaking down. In the Greek context, with the crisis of the ESY during the meltdown of public finances in the 2010s, the continuity of caring of the implanted bodyminds broke down. I documented several such cases. Thus, infrastructural issues are reflected directly in the cyborg bodyminds (Pateraki, 2019, 2022).

And while, in the process of calibration, caring appears as attunement, in the process of battery replacement, caring means maintenance, and DBS becomes a recipient of care. Caring for technology, assuming responsibility

for the maintenance of things, becomes thus, as for Maria Puig de la Bellacasa (2016, p. 43), an ethical obligation. In DBS, as caring for the patient includes care for the technology, this ethical obligation becomes more pronounced. If DBS sits idle, caring for the implanted patient is failing; the boundaries of caring and maintaining thus appear blurred in implanted bodyminds.

An attendant caring practice concerns persons with a rechargeable system. In this case, the needs of DBS impose inaction on the patient who must temporarily immobilize him/herself. Antonia finds it hard to remain still for hours, in order for her implanted device to recharge. “Being charged” is an imposed habit for the patients implanted with rechargeable batteries. Thus, Martha feels bored as she has to sit completely immobilized for an hour and a half every two weeks, wearing a special vest. Kalia, a 74-year-old woman I interviewed by phone, finds this task equally difficult: “The charging of the battery is intolerable. I have to remain still, while the vest is charging, and with my slightest movement, I hear this awful sound. I keep forgetting [that I’m charging] and I have to do it all over again. A very boring, but necessary procedure.” (Interview with Kalia) Besides being boring, charging then reminds to the patients of the presence of the device. When charging is interrupted, a buzzer sounds, and the process must begin anew.

There are finally cases when stimulation fails. Elias’ (62-year-old) device is idle. When I met him, he was bedridden already for a year in hospital, as his battery could not be charged. He “feels awful” with his non-functional device and the maximum dose of medication. Medical technologies, just like any other technologies, occasionally fail or malfunction (Schweitzer, 2015; Mol, 2008). And like the collapse of the network mentioned by Star, the collapse of stimulation in DBS can also be informative.

Because what fails is a part of Elias. His case provides new understandings of cyborgization: should his hospitalization be considered a form of caring for him, or a sequence in repairing his implanted device? In both cases, the liveliness of DBS and of Elias himself appear tightly linked. Caring for Elias refers indistinguishably, on the one hand, to the tending to his bodymind, while on the other to the repair of the idle device inside him. The boundaries between caring and maintenance thus appear blurred in cyborgization.

So far, I have focused on the dependencies and the distribution of agency in the cyborg bodymind. There are, however, other actants in play

that affect the “liveliness” of DBS. These in turn, require the intervention of another technological caring practice, this time related to spatiality.

### 3.3. Disentanglement Work as Caring

After having spent a week in a hospital in order for her device to be calibrated, Nassia recounts that she found herself, two days later, with her DBS suddenly off. She told me: “After my last hospitalization, when the neurologist completed the calibration, for a curious reason, the DBS powered down.” (Interview with Nassia) Nassia’s doctor, after a brief talk with her, attributed the shutting down of the device to her coming close to a large magnet she used in sewing. The issue of this type of interference is well known by health professionals and all the instruction manuals of DBS manufacturers mention it.

EMI causes IPG to halt, or deregulates it. The dance of agency is then disturbed by the intrusion of the unwelcome actant, as the alignment supporting the process of stimulation is disjointed. In such cases, the stimulation usually ceases, while the symptoms of PD return immediately in full force. For Nassia, this incident alerted her once more about the vulnerabilities of cyborgization. As this actant is invisible, this incident still impresses her; she commented that sometimes it puzzles her a little bit.

In Nikos’ case, a strong EMI had an almost lethal effect. Apparently interacting with a wet and electrified environment, his device started malfunctioning and his body went out of control (Pateraki, 2019, 2022). Instead of subduing the liveliness of DBS, the EMI enhanced it, and the erratic signals sent to the brain caused havoc. This episode depicts the dangers of overstimulation in implanted patients (Dustin, 2008, p. 301), and was resolved only with Nikos’ immediate hospitalization.

Thus, the cyborg bodymind must be protected against the intrusion of this unwelcome actant. Avoiding EMI can, then, be considered part of technological caring. Such a theorization could start by expanding the concept of “disentanglement work”, coined by Nelly Oudshoorn (2018, p. 172) to frame the type of occurrences inflicting harm on implanted devices. Oudshoorn comes close in defining such technological care practices, when she speaks of patients’ “everyday routines” and “intimate practices”, intended “to cope with the interactive agency of machines inside and outside their bodies” (p. 171).

Achilles feels his device reacting with the remotely-controlled garage door. His wife and caregiver Anna does not believe him. She only believes what is written in the DBS manual. As garage doors are not in the instruction leaflet of the DBS device, she disregards Achilles' experiential knowledge, even though the garage door technology is similar to other technology included in the manual, such as anti-burglary systems, and airport gates. The couple disputed this issue during the interview:

Anna: He thinks that the garage door below disturbs him. But it's not in the book.

Achilles: Whenever I come near electromagnetic fields, I am affected. When I go to the bank, crossing the doorstep tires me. And then when I'm inside I forget things.

Anna: The door affects him, yes. In the airport they have told him that. Now, I don't know if the bank has something similar. In the airport they have told him to show them his code, and then he could bypass [the control gates].

(Interview with Achilles, and Anna, caregiver/spouse)

Achilles reported numerous EMI incidents: at a fair, his device malfunctioned while he was standing next to a sound system. The agency of environment seems to have a variety of effects on him, both physical and mental, influencing his whole bodymind. When I asked him if he manages to avoid such places, he answered me: "Not always. I try to, but there are still places that I cannot avoid." Thus, Achilles stays alert as to which conditions might affect the functioning of his device, without being always able to control them. That issue, the invisibility of EMIs, is also raised by Themis, a 58-year-old former IT worker I met twice at his home in Attica:

And how should I protect myself? Since [EMIs] are invisible, I can't see them. If I could see them, I would say, OK. Furthermore, the signs and panels are not everywhere. On top of that, you worry about whether this could possibly happen at home. When I know it, yes, I can be prepared. But when I don't, what can I do? My body understands it and reacts even before I realize it; and then of course it's too late. The "evil" has started!!! (Interview with Themis)

Nassia explained that, after many such instances, her body remembers the effects of EMI, and she has become very careful. She encompasses DBS in her caring: "DBS is now part of my body, and I have to care for it! Because

caring for it is caring for myself!!! [...] Ehhh, you see DBS has expanded the list of the things I have to avoid, in order to live well.” (Interview with Nassia) For Nassia her caring and caring for DBS are indistinguishable.

#### **4. Conclusion**

In this article, I examined technological caring, focusing on DBS implanted patients’ experiencing PD. I consider that, after implantation, patients become entrapped in “dances of agency”, dialectics of resistance and accommodation, imposed by the requirements of technology, and the progression of illness, while striving for functionality. As human and technology “live” under the same skin, cyborgization, far from being a seamless process, shapes new modes of caring that need to be accounted for. I argue that these modes relate essentially on the “liveliness” of the actants involved in this dance. Finally, I present the enlarged caring practices imposed by the tradeoffs of cyborgization. The iterative process of calibration as “tuning”, the timely replacement and in some cases the regular charging of the battery as “maintaining”, and the necessity of avoiding EMIs as “disentangling”, should all be considered as technological caring.

Concluding my article, I argue that the study of implanted bodyminds highlights the variability of the caring practices involved. Taking DBS as part of caring, both as a means and a recipient of caring, I showed the materialities, the financial resources and the work that implanted bodyminds need in order to be and to remain cyborgs. The breadth of caring expands, as it must include tending to the technological parts. And, as maintaining the technological parts should be considered part of caring for the cyborg patient, the boundaries between care and maintenance are blurring, while categories are becoming diluted. Maintaining the technology is caring for the bodymind, while attuning the biological and the mechanical becomes a key caring practice. Rendering visible the entanglements of the implanted bodyminds and their dependencies on complex webs, I showed the complexities of technological caring.

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### **Présentation de l’auteur**

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