

Bodily Felt Freedom: an Ethical Perspective on Positive Aspects of Deep Brain Stimulation

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Abstract The critical aspects of deep brain stimulation (DBS) are usually the focus of the ethical debate about the implantation of electrodes into the brain of patients with Parkinson’s disease (PD). Above all, potential postoperative side effects on personality caused by DBS mark the debate. However, rehabilitation of agility and mobility by DBS can be posited against critical aspects. Therefore, the purpose of this article is to emphasize the hitherto neglected positive aspects of that technology. A detailed study of the rehabilitation of controlled movements will thus be the object of this article. The possibility to move again in a controlled way will be discussed as *freedom of movement*. The concept *freedom of movement* is being linked to the observation of feelings of euphoria and joy that can occur after surgery for patients with PD stimulated in the subthalamic nucleus (STN). This is done based on phenomenological analysis and qualitative interviews, in which the relation between freedom of movement and feelings of joy becomes clear. The aim here is to show that these feelings of exaltation express an essential feeling of freedom – a *bodily felt freedom* – which is grounded in movement and can be regained by STN-DBS.

Keywords Morbus Parkinson · Deep brain stimulation · Qualitative interviews · Bodily felt freedom · Freedom of movement · Autonomy

Introduction

The “technification” of the brain, for example by implanting electrodes, has stirred up a lot of attention. Hopes are rising, but also fears: novel ways to control human beings could be invented and man would become an aboulitic, technical machine. La Mettrie’s view that the human being is a biological machine has reached a new level in this mechanistic perspective [1]. Consequently, human freedom would not be a subject of debate anymore: a “robot” is not free, a fact widely agreed upon.

Patients with PD have been successfully treated with electrodes stimulating core areas of the brain since the late 1980s. The treatment helps to reduce the cardinal symptoms of PD. Due to the loss of dopamine secreting neurons movements slow down (bradykinesia, hypokinesia, akinesia), muscles grow stiff and rigid (rigor), patients start trembling heavily (tremor), and, in later stages, their balance is distorted. Initially, drugs containing L-DOPA (a pre-cursor to dopamine) are the most effective therapy. In the course of the treatment, however, patients start to suffer from fluctuations between a state of good mobility (on-phase) and bad mobility (off-phase) and uncontrollable and excessive movements (dyskinesia).¹ If this state changes repeatedly during the day, DBS is considered as a further option for patients who fit the medical criteria.² By now, many patients agree to this

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¹ The fluctuations in the effects of the medication are due to the difficulties in keeping the level of dopamine constant in the course of the disease.

² By now, DBS is also used in early phases of the PD [2].

form of therapy and become – coming back to the idea of “technification” – direct witnesses of the cross-linking of man and machine.

Some patients of the group I interviewed reported that they feel controlled from the “outside”; a feeling that can arise after STN-DBS implementation and is discussed in the ethical debate about STN-DBS [3–7].³ Patients described unintentional and undesired movements (squatting down involuntary) or the feeling of getting “a kick in the butt” when the neurologists increased the frequency of the electric impulses of the device. There were also sudden aggressive impulses that gave patients the impression of being controlled externally; one person could hardly control the impulses and reported that they “came from *god knows where*, but not from me”.

Nonetheless, patients put positive aspects in the foreground; the new opportunities or abilities offered by DBS are essential. Moreover, the feeling of being controlled decreased with time, and the positive changes remained. This article will reflect upon these positive changes and integrates the findings drawn into a theoretical framework.⁴

After DBS surgery, some patients describe feeling extremely happy and “new born” (see example: “After deep sleep”). This traces back to the effect of STN-stimulation, which reduce the deceleration of movements, the stiffness and the tremors to almost zero. Whereas they had to constantly fight against resistance while moving in the off-mode, the drag is now being suppressed and they can move smoothly again. These patients are buzzing with excitement: they are *euphoric* about the experience of being able to move themselves so easily again and about regaining control over their bodies. The feeling of being the master over one’s body again is also being amplified by the new possibility to regulate the changes between the states of good mobility (on-phase) and bad mobility (off-phase). Now, they feel like they can rely on their body once again. They experience *joy* now that their body follows their will. At this point, the disease itself loses its omnipresence. Their lives regain normality.

In this article, the euphoric state that occurred after surgery within the reference group, and the likewise

observed joy, will be analysed, since they offer insights about the potential positive aspects of DBS. The aim is to discover deeper layers of those two closely related feelings. The first finding is that these feelings are the expression of a sense of freedom linked to movement. That is, patients begin to *feel free* again because they can *move freely* again; out of the ability to move emerges a feeling of freedom [9]. The article will focus on this pre-reflexive *bodily freedom* – which is not an intellectual freedom – on the level of embodiment, the level of the *Leib* (lived body), in phenomenological terms, [10–16].

As we will see, this form of freedom develops already during infancy, and is experienced as joy. The child develops *basic autonomy*,⁵ that is, he becomes independent from the environment and self-dependent as he learns how to use his body.⁶ From a genetic viewpoint, bodily freedom is a pre-stage of *rational autonomy* (here in the sense of self-control [18–20]). As a first step, the development of human movement allows certain body parts to rest and others to move [21–23]. This capability matures to a degree that it is possible to stop movement entirely. Thereby, according to anthropological interpretations, *space* for cognitive thinking emerges [23–28]. In this space of thoughts, the “principle of inhibition” also applies: just as certain body parts are inhibited in movement, with respect to thinking, certain thoughts are blocked in favour of others. In order to capture the change from moving activity to thinking activity, we could also say, that there is some *sublimation* from one level to another (Freud) [29, 30]. For patients with PD, this sublimation seems to change: you observe a synchronization⁷ of activity and inhibition, so that, on the one side, movement and, on the other side, thinking activity are blocked. DBS seems to rupture this synchronization, so that body movements are re-enabled. The same is the case with thoughts,

⁵ The concept of “basic autonomy” (basale Autonomie) refers to Christian Weingärtner’s work [17]. He introduces the concept in the discussion of the autonomy of challenged people.

⁶ Bodily felt freedom and basic autonomy are two closely related concepts: bodily felt freedom denominates an aspect of basic autonomy, namely the feeling of being free, while the concept of basic autonomy adds a reference to the environment, that is, independence from it. Generically, bodily felt freedom first enables basic autonomy, later it is being incorporated in the phenomenon of basic autonomy.

⁷ The terms “synchronization” (and also e.g. „inhibition“and “activity”) comes actually from medical literature; it is e.g. used to describes the beta oscillation of PD [31, 32]. To what extent the descriptions of the article match with the neurological findings cannot be assessed here.

³ The patients in this study all undergo STN-DBS. For the sake of simplicity I will from now on use mainly the term DBS.

⁴ Ineichen gives an overview of works that addresses positive aspects of DBS [8]. See also Gilbert [5].

which gather momentum again. However, DBS also seems to unleash forces that prevent the patient from inhibiting their movement in favour of calm thinking activity. After surgery, they are too “amped”, too euphoric to achieve a state of reflection: they want to be “on the move”, as they say [33]. One patient described that he sped up his decisions, because he was filled with the thought of “you just do it now”⁸ and that thereby he felt being out of self-control.⁹ The sublimation of body activity into thinking activity seems to be reduced in euphoria. The *feeling* of freedom,¹⁰ however, awakens a renaissance with this amplified body activity: the patients can move freely again, and they feel very good about it.¹¹

Since euphoria can be conflicting for patients (besides the feeling of freedom), the study of the positive aspects of DBS should exceed the feeling of euphoria and investigate whether DBS could also lead to a normal movement activity that allows transferring energy into thoughts. I claim that this is the case, when patients experience joy, since joy is the expression of a controllable, medium level of movement activity.

The renaissance of the feeling of freedom experienced in euphoria or joy will be expressed through the concept of *freedom of movement*. This concept will describe the state of patients with PD after surgery, in which they are freed from mobility constraints and thus feel free again. The term *freedom of movement* will be used as a concept for the positive aspect of DBS, that is, the regained feeling of being free.

The article structure is as follows: firstly, I will elaborate on the method of the research conducted, namely the interviews. In the following section, the concept of *bodily felt freedom* I will introduce to

create a suitable starting point for understanding the loss of movement control because of PD. Here, I claim that freedom is felt through movement and expresses itself in feelings of joy. This will be exemplified by the development of movement and mobility in infants. Then, I will articulate the range and importance of what it means to lose the ability to move freely due to PD. In support of that idea, I will present excerpts from the interviews, in which patients describe how they felt “immured” before they had surgery. Next, I will show the effects of DBS on the movement-based experience of freedom. Here, I will apply the concept of *movement of freedom*. It will give us a starting point for the analysis of further excerpts from the interviews, which will elicit how patients feel when they are able to move freely again after surgery. The feeling of euphoria that dominates their subjectivity after surgery will be examined and linked, in retrospect, to the movement-based experience of freedom. Lastly, I will explain how strongly DBS is connected to the movement-based experience of freedom – which will allow us to make a statement about the question, whether DBS enables normal activity of movement expressed in joy.

Method

The foundation of this article are 8 recorded qualitative interviews (narrative or partly-structured) with an overall length of 12 h, from PD patients with STN-DBS [39]. Seven men and one woman agreed to participate in the study. The patients spent at least 7 months under stimulation when interviewed.¹² The second source is a recorded focus group conversation [40].¹³ All interviews and the focus group were translated from German. A few excerpts from the interviews and the focus group will be included in this article.¹⁴ The analysis of the interviews led to the

⁸ During a state of euphoria, one patient heard himself repeat: “You just do it now, I said. I said, that’s not right! Yes, you just do it now! Because I would have.... it came...uh, I did *want* this. (One) could say of course, well, maybe it influences our will, our human desire, the stimulation”.

⁹ There might be a potential link between euphoria and increased impulsivity, which leads to imprudent decisions [34, 35].

¹⁰ In this article, I will not discuss relation between movement activity and thinking activity in further detail. This will be part of my dissertation about the bodily felt freedom (leibliche Freiheit).

¹¹ The observation that basic autonomy is artificially created raises the problem on how to evaluate this “external” factor [5, 18, 20, 36]. Is the feeling of freedom, caused by DBS, only an illusion? At this point, the question cannot be sufficiently answered. However, to experience the specific feeling of freedom conceptualized in this article, one does not need to be free in terms of metaphysical conditions [9, 20, 37, 38].

¹² A period of time spent with stimulation was important for the article in order to find examples for bodily felt freedom expressed in joy after the surgery.

¹³ The conducted focus group took place during the symposium and included three patients, with whom I had already conducted interviews, two doctors and conference participants.

¹⁴ The study is a project that is part of the Cluster of Excellence *BrainLinks-BrainTools*. It focuses on the ethical implications of neurotechnologies (Mechanized Brains) and an offshoot to examine the value of movements with respect to movement disorders. The principal investigator is Prof. Dr. Oliver Müller.

formulation of several theses, one of which became the initial point in form and content for the symposium (January 2017 in Freiburg i. Br.) and, eventually, the subject of this article. With respect to the excerpts, I narrowed the focus to the most significant results to remain within the scope of the problem. The analysis will be about the statements that the patients have made about their feelings when they could not move anymore (before surgery) and when their mobility was restored (after surgery). The focus is thus the “kinaesthetic feeling” of movement, or the felt movement [41–43].

The interpretation of interview statements will be related to Arnold Gehlen’s *Anthropology of Plasticity*, in which the exceptional position of the human being is grounded in his biological deficiency (in comparison to animals), which makes him a cultural and learning creature [44]. His approach helps explain the concept of *bodily felt freedom* in the context of the development of movement in infants. The philosophical assumption is that infants must compensate for reflexes and instincts that animals still have through learning, e.g. learning how to walk [22, 23, 28]. To summarize the conceptual framework of the article, I will use an expression from Edith Stein: “He [the human being] can and should form himself” [28]. Her way of conducting impartial research in reference to Edmund Husserl and Thomas of Aquinas has been a great help to understand the human being in his particularity and to follow his traces. Her fundamental claim regarding the phenomenological method is (before the background of Husserl’s approach):

“[...] to focus on *the things themselves*. It’s not about asking theories to get answer about questions; turn off everything that you hear, read, have already constructed by yourself, but approach it with an unbiased view and draw it from immediate intuition” [48: p. 28, my translation].

Thus, phenomenology is a “protection” against one-sidedness and persistent theories, such as that of *nihilism* (which, regarding Stein, must be overcome if we aim to understand the nature of human beings) [28].

As a first step, I have phenomenologically opened up the mode of existence of patients with PD. Then, I embedded the observations that I made in a larger phenomenological framework (development of children, euphoric feelings in athletes). As a second step, I

combined my results with other observations (Gehlen, Stein, Seewald, Schmitz, etc.).

Another important author will be Jürgen Seewald and his approach known as *Interpretative Psychomotoric* [14, 45]. In this approach, movements are the most important way to get in contact with the world. Those three approaches are a starting point to develop a genetic view of felt freedom.

A further important point of reference will be the *New Phenomenology* according to Hermann Schmitz. The author examines how daily-life experiences like feelings, atmospheres and situations are sensed with our own *felt body* (Leib) [13, 46]. The present article will take the *felt body* as the foundation to develop the concept of *felt freedom* based on movement as a previously unconsidered kind of freedom. This approach, however, does not pursue a genetic view, which is why it needs reinterpretation and integration into a genetic approach; this will change the perspective on the felt body.

In the following section, I will address the natural movement-based feeling of freedom to obtain a basis for the examination of the relationship between the effects of DBS and this aspect. I will refer to the development of movement in infants, which will serve as an illustration for the basic feeling of freedom. The claim is that the experience of freedom is the result of a learning process; the special aspect of the movement-initiated experience of freedom is its *primacy* and its *bodily felt character*.

The Feeling of Freedom Based on Movement

We are born with a range of instincts (sucking reflex, tonic neck, righting reflex, gripping reflex, stepping reflex, etc.), which, however, disappear after a while. In the first half-year of our lives, we overcome many of our instincts and must regain their former instinctive competences through repeated training through our own will power [28, 44, 47]. Thereby, we reach higher degrees of freedom in comparison to animals, because we gain possibilities by this compensation [23, 44]. Consequently, we can use our capabilities in an intentional and directed way – a phenomenon that relates to the development of movement.

The so-called “stepping-reflex” disappears after around three months. In comparison to quadrupeds, that achieve stability through their “stepping-reflex” and

their physiology right after birth, infants must find their balance and stability on their own [22, 41]. Therefore, they need time to come *to themselves* in a bodily respect. They coming *to themselves* because they gradually grow a *sense* or *feeling* of themselves alongside the development of their movements [14, 45]. What they develop is a *pre-reflexive* body that is *felt*, a *felt body* (Schmitz) [13].^{15,16}

Since their body is not under their control at the beginning, they need to *seize* their body. If an infant finds something interesting in his environment, he wants to get there whatever the cost. In these moments, the infant needs to seize his body voluntarily, that is, he permeates his body with his will.^{17,18} That the infant needs to seize his body implies that will is not limited to the body. Will is, however, still uninhibited, not captured by the self; it is “unfocused”.¹⁹ The body is therefore, at first, not seized from “within”. The infant is still entirely interwoven with his environment.²⁰

Whereas we can observe that animals do not have to summon a certain amount of will power to move and control their bodies after birth, infants do need their will to be able to move. The resistance that the

infant experiences, because the body does not yet follow his will initiates a sensual perception within the borders of the body.²¹ The resistance through which the infant learns to sense himself is anatomical; his body architecture is very inapt considering the forces of gravity (it is not supported by four legs, but by two feet) [22, 23, 44]. The infant has to find the “force-line of the vertical” (“Kraftlinie des Vertikalen”) by summoning his will (Seewald) [45]. At the beginning, the infant is lying helplessly on the ground, at gravity’s mercy, then he obtains the ability to crawl – and with it, he discovers the most stable position with respect to gravity. Eventually, the infant starts to slowly erect himself and loses all his “natural” stability [22]. The inspired feeling of himself, however, helps the infant to find his balance. If the infant stands and walks, he has detached himself from the ground and has found the necessary inner stability. Now the child can counter the constraints of gravity and steps into an empowered relationship with its forces from the position of verticality [22, 28].

When the infant gradually finds his balance, something essential happens: the objective body *weight* that is constituted by gravity is neutralized by erecting the body. Body weight – which is experienced as heaviness and inertness when the body is not sufficiently felt and balanced – is neutralized in such a way that no heaviness is experienced anymore (for activities that do not have to be tackled too much against gravity). Body weight is not detected anymore; the child is in balance, the body is a *felt body*.

This entire process of erecting oneself expresses itself in children in their glaring eyes and bouncing limbs [14, 22, 41, 49].²² There is an immense *joy* to be observed when children gain control over their movements. Their joy increases alongside the growth in the potential to “be mobile” and reaches

¹⁵ The reflexive aspect, expressed in *felt*, cannot be found in babies. They are still totally engaged in sensing and only develop a certain distance to sensing with time.

¹⁶ The *objective body* – which in the phenomenology of the body is different to the *felt body* or *lived body* – is not central regarding the development of movement in children, because the objective body presupposes a reflexive self [10–13, 15, 16].

¹⁷ To get more insights about the observations regarding will in the development of infants, we can connect will to Stein’s conception of the soul as the principle of what forms matter (the body is an expression of that). As we can see, there is a *will* to form matter. Without this kind of will, there is no plausible explanation for why beings want to stay alive, why they want to live; we can therefore also speak of the *will to live*, which captures the body. The fact that such views are not common in science these days (anymore) is not due to the “Sache” but to biases or a limited perspective, as Stein would say [28].

¹⁸ Schmitz would not agree with Stein’s view of the body and the thesis on the will introduced here. He uses his “bodily” terminology. That is why the term “felt body” used here goes beyond the understanding of Schmitz. However, since I think “feeling” is significant to *bodily felt freedom*, “felt body” seems to fit better than “lived body” (even though the felt body is actualized by the will to live).

¹⁹ The word “unfocused” originates from a patient who will be quoted in detail later.

²⁰ Adopting a term introduced by Hermann Schmitz, we may say that infants still live in a *measureless expanse* (maßlose Weite). He speaks of this, however, in the outcome of a man who has already come to himself (his view is not genetic). On this basis one could reach a state of measureless expanse, which means to *get out of the body* (Ausleibung). Compare also Seewald’s discussion of *being fused* (Verschmolzensein) versus *having a core* (Kernhaftigkeit) [45].

²¹ It is usually assumed that self-awareness in its basic form develops from interaction with the environment [48]. This article in contrast, proposes the view that the sense of oneself develops first through “interaction” with one’s own body.

²² In Schmitz, the felt body becomes the shelter of many emotions, which describes the vital state of a person. Here, the focus is on the “emotions” which are felt through movements. The principal factor is the feeling of freedom, which could be associated with the concept of “Weitung” (widening) or “epikritische Weitung” of Hermann Schmitz [46].

its peak when they experience the “force of the vertical”. They no longer submit to gravity and joy is their reward. To say it with Stein: “The vertical ascension is the highest triumph of creative power over matter” [48: p. 43, my translation]. Children, we might say, are the bodily expression of this triumph. With respect to the development of movement for infants, joy can be considered as an expression of the existence of their felt body [14, 41]. It is an expression of the ability to counter gravity [41]. A child whose possibilities to move have evolved to stand on his own feet; he has gained autonomy on a very basic level [45].

Bodily Felt Freedom

Joy points to an experience of freedom that is felt when one lifts out the body from the pull of gravity: the body has been posited in a new way against it via the “vertical”. This experience of freedom evolves together with the development of movement, that is, the development of the *felt body*. The felt body, as could be formulated, is the “*space*” of the feeling of freedom. We can now describe this kind of movement-based freedom as a *bodily felt freedom*. After having acquired this bodily felt freedom, it fades into the background of consciousness and is latently felt.²³ Nevertheless it is forever (regressively) linked to the feelings of delight and joy of these early days [45]. Doing sports or while dancing, this feeling can be *reignited* as taking pleasure in moving and the joy about movements. This joy about bodily felt freedom is the interface towards certain occurrences of euphoria (e.g. the exaltation of running = runner’s high), which are closely related to movement and which create the feeling of effortlessness. This will be discussed in further detail in section “Euphoria based on movement”.

Since human being has a distinct desire for freedom, the first experience and sensitivity for this freedom, created during the process of learning how to walk, is essential. If you remove bodily felt freedom, e.g. due to sickness, the effects on the attitude towards life are necessarily grave.

²³ The unremarkable feelings of freedom are comparably to the “feelings of being alive” [48].

Below I will present excerpts from the interviews in which patients describe how it feels when the body does not submit to their will anymore.

How Does it Feel to Not Be Able to Move Freely Anymore?

The symptoms of PD, slowed down movements, rigor and tremor create a typical body sensation. For this feeling, the patients used emphatic images:

- **Immured**

W: “Yes, well, that is, when I cannot move myself anymore, what comes to my mind... immured in the ground, and today the bell has to be finished... the sweat ran hotly from our foreheads, you know, you really feel like being immured”.

- **Trapped**

K: “You are, so to say, trapped in your own body”.

- **Water**

L: “Trying like... having the feeling of standing in water and trying to run fast, the resistance of the water blocks you automatically”.

- **Damp**

P: “As in winter, when you have made lots of snow balls, then your hands are so very damp, aren’t they? This is the feeling you have in your whole body, [...] so damp and always against resistance”.

While the first two adjectives, “immured” and “trapped”, describe how the bondage of not being free to move feels with PD, the other two, “damp” and “water”, express how it feels to move despite the bondage and drag. Moving under restriction of movement means going against the limitation of their own body. Thereby, the body is experienced as a resistor.

To go against a resistor makes every move exhausting and heavy. In the next quote, a patient talks about an artistic display that would express PD. Here,

they summarize feeling of resistance and heaviness in the expression lead plates.

- **Lead plates**

W: “I’ve been in the Hygiene Museum in Dresden once, there was a man, a mannequin dummy, he was wearing a white suit with lead plates in it, from top to toe and below there was an inscription, very banal, this is how the Parkinson patient feels, [...] well, that hit the nail right on the head”.

This quote illustrates that patients with PD have a heavy burden to bear. Their body is like a lead weight, so moving around freely is no longer possible.²⁴

The Degeneration of the Felt Body in Patients with PD

Due to the deceleration of movement and the rigor and tremor deriving from PD, movements are experienced as heavy and difficult. This is particularly striking when patients depict this experience in terms of images (lead-plate). If we apply the premises about the evolved felt body explained above, we can ascertain this: the genetic process towards establishing the felt body degenerates. That is why the body cannot seize one’s will anymore in the right manner. They begin to embed and interweave themselves into their environment again; there is a kind of *Ausleibung* (getting out of one’s body) of the will [46]. One patient reported that he experienced a stronger connection to his environment as his symptoms increased.

- **Transcendence**

B: “One already had a certain kind of trans, how do you call this? What...”

I: Transcendence.

B: Trans, yes, tran, experience of transcendence, yes, [...] so, this transcendence, well, this is, well, it is also a form of not being focussed”.

As the will cannot seize the body enough anymore, they lose control over their body. Having already develop their movement repertoires in early childhood, they struggle to regain control – their body, however, does not obey anymore:

²⁴ It is important to note that PD is not always negatively experienced by patients [5].

- **Cannot control**

B: “And this, I believe, did also make me feel really down, very down, very bad this feeling, I cannot control my body or the tremor with my will anymore”.

That the body does not obey their command indicates that the felt body is in decay. Patients lose their balance; they are off kilter. This succeeds a new loss of ground to the forces of gravity. As they are not in control of their body anymore, the objective weight (body weight) becomes increasingly dominant. The effects of the gravitational field of the earth weights on them, while during the development of movement in childhood such effects had been neutralized. Both the limited access to their body and the earth with its gravity prevent the movements of the patients. Their body can only be controlled through significant efforts and under strain. Their body refuses obedience and does not follow their will due to the disease. This is what leads them to have feelings of being unfree. The latent feeling of joy, which emerges in a healthy person, is replaced by feelings of “helplessness” and “anger”. Every patient spoke of the great suffering they experienced. They used expressions like: “that’s so terribly frustrating”, “an awful situation”, “it wears me down”, and “I was depressed”, feelings, which often resulted in thoughts of suicide. The prospect of getting therapy that will restore their freedom of movement appears merciful against this backdrop. In fact, their psychological state reverses after surgery. The patients have been extremely happy and they feel free again.

In the following section, I will show that DBS can restore this feeling of bodily freedom. For this purpose, I first will introduce the concept of *freedom of movement*.

Freedom of Movement

Against the common meaning of freedom of movement in German,²⁵ which essentially refers to spatial limitations, I will refer the concept of freedom of movement to

²⁵ The German dictionary term “Bewegungsfreiheit” primarily denotes the “space which is available to a sufficient degree to move arms and legs”. “Space to move around or roam in”, “free run” and “leeway” are synonyms. In a metaphoric sense, freedom of movement means “independence”, “without constraints” or “autonomous action”. “Bewegungsfreiheit” denotes also a basic right “to enter every admissible place” (Art. 2, Abs. 2, S. 2 German Grundgesetz).

physical limitations and limitations that have an impact on mobility and movement. The main focus is not the sufficient space to move but something more fundamental: the ability to execute movements. To frame it with the words of a patient:

- **Freedom provided by the body**

B: “You still need a certain form of freedom that is provided by the body before you can deploy your will again”.

The *body* in the context of movement disorders is what *space* has been in the conventional understanding. Just as we can change spatial conditions in favour of our freedom of movement, the conditions of our course of motion can be altered through certain means: the capability to move in people with PD can be “corrected” by medication or by implanting electrodes. Thus, I will use the concept of *freedom of movement* in the context of movement disorders and with respect to the application of DBS. Hence, freedom of movement means to move without bodily limitations (in the best case). It’s an expression of restored *basic autonomy*.

Below I will address the feeling patients have when they regain their freedom of movement. By looking closer at this feeling, the positive aspect of DBS becomes apparent as a central factor for quality of life. In the following sections, the interview extracts give information about the dominant feeling after surgery.²⁶

How Does it Feel to Be Able to Move Again?

Thanks to the reduction of the symptoms and the regained control over their bodies, patients feel like a new version of themselves.

- **After deep sleep**

I: “Can you explain how it feels to be mobile again, in the best case?”

O: Yes, in contrast to before, incredibly good! I think about the immediate time after the surgery, it was already on the day of the surgery, I was

²⁶ The surgery already has a positive effect on many patients, even without activating the stimulator. This is called the Micro-Lesioning-Effect (MLE). The possible difference between the MLE and stimulation will not be discussed here. The focus of this article is on the feeling that appears through the regaining of freedom of movement.

still euphoric like (name of the physician) said, so I had to restrain myself, but I was like new born. You can, I was...for six years, I’ve been watching, as I said, how I deteriorated, and suddenly, something happens, you are in a deep sleep right after you get the device implanted, and then you wake up, and you can move again, that is an incredible, incredible feeling.

- **Take on anything**

B: “Well, it is a very demanding surgery, [...], however, I felt very good, I could have taken on anything. [...] The feeling was euphoric”.

- **Euphoria about the new situation**

K: “Of course, this was great, suddenly, I could jump again, and make little hops without falling, and this was motivating, of course and you can feel this euphoria about the new situation, yes, it is really working, this plays a really special role”.

The quotes suggest that the capability to move again leads to euphoria. The patients talk about themselves as being euphoric. At first, however, there is no mention of joy. Why is the dominant feeling euphoria and not joy? To answer this question, I will shortly examine the feeling of euphoria that is based on movement in a more general way. Similarly to joy, euphoria will be discussed in the context of the capability to move, though not based on movement development in children. That is because euphoria already requires a felt body.

Euphoria Based on Movement

As I have argued, the capability to move influences the feeling of freedom. The capability to move gives a latent feeling of freedom; this feeling can be excited again and in a more intense way. The development of movement in infants is actualized through intensive bodily activity and can, so to speak, be relived. Euphoria, I claim, is the expression of a will that hyper-engages with the body in order to reconnect it – in a regressive way – with our childhood experiences of freedom. Many people demand a more intense feeling of freedom. This can be achieved, for example, through extremely long running (runner’s high) or while dancing, when even extraordinary movements can be exercised with precision and

control. In both cases, the will seizes even the “last corners” of the body; the body is being “over-captured”. Will takes hold of the body (compels the body) and sets aside resistance. As a result, an induced feeling of power, effortlessness and lightness, a feeling of being relieved of any heaviness makes one feel extraordinary free. Understandably, this generates the (self-overestimation) view: “I can do everything” [33, 36, 50–52]. Against this backdrop, I will now take a closer look at euphoria in patients with PD.

Euphoria in Patients with PD after the Surgery

After the surgery, we have seen that patients can be very euphoric. Why does this phenomenon occur? DBS can potentially set aside the loss of control over one’s own body. That means, the will, which had to fight for access to the body, has resumed its influence on the body (or DBS actually forces it). The patients experience a certain artificially restored “power” and “ease” with respect to their own body; a feeling healthy people usually experience when they put their body into action, e.g. via sports. Euphoria is amplified by the fast change – from yesterday to today – between the old (heavy body experience) and the new state (light body experience).²⁷ Shortly after the DBS surgery, there is an intensive feeling of freedom based on freedom of movement. This can be accompanied by the feeling of being able to do everything (what seems to be a self-denial considering the persisting disease). Thus, freedom of movement is related to a “restorative sense of self” [36]. Linked to this, it seems to affect even social behaviour. One patient reported that he felt more at ease in his interactions with other people and his fellows:

- **Free**

K: “On the other side, however, it was a little bit positive, it wasn’t so bad at all because I was more open, uh, more free to engage with other people, for example. Not so, not so shy, inhibited, or reluctant, well, it has its advantages”.

He admits, however, that euphoria is only an advantage if the inhibited behaviour does not dominate, i.e. he

²⁷ Euphoria, however, is also a phenomenon known to occur because of medication. Medication too, can cause relief and a fast change between body control.

is able to control it. When he could not (although he wanted to) control the state of euphoria, he felt externally directed, followed by a feeling of alienation [20, 33, 36]. – The feeling of being able to do everything can turn into a feeling of being controlled from outside.²⁸ Thus, the identification with euphoria only works to a certain degree.

Self-Estrangement Caused by DBS

Other patients reported their experience of the negative consequences of euphoria, that is, its compulsive aspects. The inhibited manner appears as uncontrolled, aggressive or childish behaviour. They experience eruptions, stick their tongue out at other people, giggle uninhibitedly and make frivolous jokes. These patients described extreme states of being pumped up, and they developed different addictions (sexual addiction, shopping addiction, compulsive gambling, compulsive car racing).²⁹ For all patients, euphoria decreased after a certain period, e.g. by adjusting the patient’s devices and the regulating mechanisms of the organism itself (as the patients claim). Still, the urge to be active stayed as a tendency as long as the symptoms of PD remained in check by DBS. In this group of patients, I observed an extraordinary (voluntary) social and civic engagement. The addictions also remained. – A complete reduction of euphoria is not likely and would probably also worsen the course of motion. The state of euphoria, besides its positive qualities, bears the risk of leading to an uncontrolled manner of behaviour – to a loss of self-control – which is considered as negative within the reference group.

Taken from an ethical perspective, there is a certain conflict: although we can claim a basic form of freedom, other forms of freedom, like rational autonomy, could be compromised. There could be a “risk of altering decisional competence” as Synofzik et al. state [33].³⁰ This article can interlock with this result: because the ability to inhibit movement is lowered due to euphoria – the desire to be “on the move” is too strong – the capacity to control thoughts is reduced [28]. The patient is losing decisional

²⁸ In the debate the effects of euphoria would be classified into the range of *internal* coercions [33]. The patients, however, feel controlled from outside.

²⁹ These addictions can also occur as a result of the therapy with drugs.

³⁰ It must be noted, however, that the patients in this study are stimulated in the nucleus accumbens, whereas the patients in the present study undergo STN-DBS.

competence and that is why they have feelings of being controlled from outside. From an ethical perspective, the conflict goes even deeper: to a certain degree patients can identify with the novel way of being active (“I can do everything”), so that they feel not controlled from outside, but free [33, 36]. Nevertheless, as long as patients cannot change easily into thought activity, because they are too active in bodily respect, their capacity to control thoughts is impaired. Here, the patient feels free, without knowing he is not (intellectually) free [36].

Decisional competence, however, is not only and primarily compromised by DBS (and medication), but also by the disease itself. The disease seems to affect the ability to create thoughts more profoundly. One patient (and others) reported how her thinking stagnated when she was in the “off-phase”, and that she lost constant access to her thoughts. This was improved by the surgical procedure:

- **Access**

I: “And after the surgery there are these moments, but more frequently, so that you have better access, so to speak.

W: Yes, yes, totally, I have better control over myself and I also have better access to my brain ((laughs))”.

Although euphoria does ask patients to contain their impulses, and sometimes asks too much of them, DBS seems to help them with regaining access to their thinking, which is a condition to make any form of decision at all. In the context of PD, DBS seems to be the “lesser evil” with respect to rational autonomy.

Since, especially at the beginning, DBS leads within the reference group to euphoric manners of behaviour that also imply compulsive behaviour, I will look at the occurrence of joy, which is an expression of a moderate engagement of the will in the body thanks to a normal control of movements: this will is neither located too far outside (*Ausleibung*) nor too far inside (*Einleibung*). Between these two poles, patients can feel to *be themselves* and forget their bodily condition. Thereby reclaiming the *felt body*, in its original form.

Back to Joy

Although patients with PD stay attached to the pathological form of euphoria to a certain degree, moments of

joy can appear in their experience. This occurs when they enter phases of normal movement control. When, for example, the patient can use the keyboard of the computer or plays the guitar as before. When their body is in a reliable relationship with their will (i.e. fluctuations have stopped, the tremor ceases), the body moves to the background. In the following excerpt, the patient describes the change from his state of euphoria, which he experienced as “pathological”, to the feeling and state of joy.³¹

- **Pure joy**

B: “So this feeling to stick out my tongue, too, in the first few days, I somehow felt like a nine-year old boy. That was strange. [...]. Well, that was, a little bit, (laughs) pathological, I guess, right? Well, this, joy, pure joy actually only arises when you stop thinking about it, about this stupid tremor”.

The state of euphoria is experienced as strange and alien by this patient. It does not fit into his self-image. He feels joy only after the state of euphoria has decreased and the tremor vanished from his consciousness. Thanks to DBS, he has the temporary experience of being his own felt body again. Likewise, the following patient describes her development towards being her felt body again.³²

- **Intact**

W: “I felt significantly better, I needed considerably less medication, and I still need less medication, and I feel very intact, I feel like being by myself again and I don’t have that feeling of alienation anymore, not a at all”.

The patient emphasizes the feeling of getting back to oneself due to DBS, which points to a bodily felt freedom. As another patient recounts, this being-with-oneself allows focusing oneself. DBS did stop the state of being fused with the environment, which this patient described earlier (e.g. Transcendence). He got his focus back; he regained control over his thoughts. The following excerpts are an example of the effect of felt body on thinking.

³¹ The surgery was over a year ago at the time of the interview.

³² She spent 8 years with the stimulation when interviewed.

- **Part of a huge wave**

B: “Well, it is totally, totally strange, so that you think, well, you are still only a part of a huge wave. While I am focussed, I am centred in myself, absolutely with myself”.

After the surgery, the patient was able to focus again – means he came back to himself.

- **Focus**

B: “[...] and, afterwards, now I am able to focus again”.

The regained ability to focus implies that he has his thought activity under control (he is able to block some thoughts in favour of others). As I argued above, this is only the case when the desire of being “on the move” is potentially controllable; if the patient is able to shift from movement related actions into thought activity, this means that his will is engaged with the body in a moderate way. The extreme feeling of freedom, which appears due to a hyper-engaged will, changes into a latent – for consciousness, almost unremarkable – feeling of freedom.

Through DBS, the patient can approximate to his bodily felt freedom, which expresses itself mainly in joy, but also in the feeling of being intact and focused. The regaining of the feeling of freedom, expressed in joy, has to be evaluated as positive from the perspective of the patient, since it evokes the healthy state before the outbreak of the disease.

Summary

It was the objective of this article to demonstrate the positive aspects of the application of STN-DBS for PD, from the perspective of the patients. For this purpose, I concentrated on the phenomenon that patients are re-enabled to move freely after DBS-surgery. It was shown that they *feel free* because of the experience of their *freedom of movement*. That movement is, to all humans in general, a fundamental factor for the potential *to feel* freedom has been demonstrated in the first part of the article according to Gehlen’s characterization of the human being as a deficient being and Stein’s claim that humans need to form themselves. Phenomenological

concepts regarding the *lived body* (Stein, Husserl) and especially the *felt body* (Schmitz) have proven valuable, at first without a direct connection to PD. The primary concern of this article was to present a very basic, *felt* form of freedom, which expresses itself in emotions of joy and is caused by the capability to move.

In the presented analysis, we have seen that patients with PD, who are very restricted in their capability to move and feel unfree because of that, can regain their feeling of freedom through DBS (although not completely). Immediately after the surgery, the feeling of freedom is expressed in euphoria. This feeling is comparable (even it is “artificial”) to the feeling that is caused by extreme sporting activity and leads to the feeling of being detached. However, euphoria has a downside: it can lead to compulsive behaviour that cause some patients to suffer. Besides the feeling of freedom that is expressed in euphoria and bears the risk of limiting rational autonomy, we have seen that DBS allows a feeling of freedom that is more latent. This moderate version has its roots in movements, which accompany life all along. This effect of DBS is experienced by the patients as positive, because they being with oneself again.

DBS rehabilitates the feeling of freedom on a very fundamental level; feelings rooted in the freedom of movement. DBS is a means to re-create the felt body next to a series of feelings of delight.

Prospect

I claimed that DBS allows patients to *feel* their freedom of movement again. The feelings of euphoria and joy have been identified as phenomena that express this experience of freedom. DBS provides an opportunity for patients to rehabilitate their freedom of movement and allows them to *feel free* again. This is a strong argument for the application of DBS – and for the therapy of movement disorders in general. This argument can also be strengthened by the capability approach of Martha C. Nussbaum [53, 54]. From that perspective, freedom of movement would become a fundamental right of patients who suffer from impairments in their mobility.

Yet, especially euphoria has its negative consequences, too. States of euphoria – even if they feel great – can lead to reckless and uninhibited behaviour and the development of pathological traits. In this sense,

euphoria would also have the effect of making person unfree. Ways to regulate this emotion are crucial to decide whether euphoria can be considered as a positive effect of DBS. If, most likely, changes in the adjustment of the neuroimplant are not sufficient, we need to come back to the power of the human being to “form himself” (Stein). This power might be strengthened by rehabilitation through programs of special remedial pedagogy, which have yet to be developed.

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Compliance with Ethical Standards

Informed Consent Informed consent was obtained from all individual participants included in the study.

Ethical Approval All procedures performed in the studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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