



# Changes in self-perception in patients treated with neurostimulating devices

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## ABSTRACT

**Background:** In recent years, qualitative changes in self-perception have been reported in individual patients undergoing brain stimulation to treat their neurological disease. We here report a first systematic study addressing these unwanted treatment effects in a semiquantitative way.

**Hypotheses:** Hypothesis 1 (H1): Changes in self-perception can be detected and documented in patients following interventions with various neurostimulating devices using standardized assessment tools.

Hypothesis 2 (H2): Central nervous-implanted neurostimulating devices (deep brain stimulation [DBS]) will have a greater impact on the patient's self-perception than "peripheral" implanted devices (implanted vagus nerve stimulation [iVNS]) and external devices (transcutaneous vagus nerve stimulation [tVNS] or transcutaneous electrical trigeminal nerve stimulation [eTNS]).

**Methods:** Application of a newly developed semiquantitative questionnaire (FST-questionnaire [*Fragebogen zur Veränderung der Selbstwahrnehmung unter tiefer Hirnstimulation*]; *Questionnaire regarding changes in self-perception while treated with DBS*) to systematically assess changes in self-perception in a single-center, cross-sectional pilot-study at the University Hospital Freiburg, Germany on 50 patients (44% male; age 50 years [range: 27–73 years]), undergoing neurostimulation (DBS, iVNS, tVNS, or eTNS) to treat Parkinson's disease or epilepsy.

**Results:** Standardized assessment detected alterations in self-perception in all treatment groups (H1 approved). This included rare *self-alienating* changes in self-perception. Unexpectedly, peripheral neurostimulation had similar effects as central stimulation techniques.

**Conclusions:** Properly designed questionnaires – like the FST-questionnaire as standardized assessment tool – can detect changes in self-perception in patients during neurostimulatory treatment in a wide spectrum of brain stimulation techniques. This may provide a strategy to systematically identify the subgroup of patients liable to experience such problems during treatment already prior to treatment decisions.

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## 1. Introduction

For more than two decades, neurostimulating devices have been used to interfere with and modulate neurophysiological processes within the brain. In the medical context, they are used as treatment options for several neurological diseases, in particular Parkinson's disease

*Abbreviations:* PD, Parkinson's disease; DBS, deep brain stimulation; iVNS, implanted vagus nerve stimulation; tVNS, transcutaneous vagus nerve stimulation; eTNS, transcutaneous electrical trigeminal nerve stimulation; FST-questionnaire, *Fragebogen zur Veränderung der Selbstwahrnehmung unter tiefer Hirnstimulation* (Questionnaire regarding changes in self-perception while treated with DBS).

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(PD) and epilepsy [1,2]. Whether these interventions may change different aspects of the patient's personality or self-perception is a matter of discussion not only in medicine but also beyond in the fields of psychology and philosophy [3–10].

Brain stimulation primarily changes neurophysiological processing of the brain with possible secondary effects on cognitive and psychological domains. During recent years, casuistic reports about changes in patients' self-perception following therapy with DBS have been published, including feelings of losing oneself, losing the aim in life, or feelings of being controlled remotely through the device [3,11–16]. Such subjective reports were underpinned by the finding that despite therapeutic success in terms of objective medical outcome parameter assessment, some patients have not been able to resume their normal life [11,17–21]. A systematic assessment of markers of such unwanted treatment effects on the patients' self-concept is thus urgently needed and has been requested by several authors [3,5,22].

### 1.1. Aim of the study, treatment groups, and hypotheses

The aim of this study was to semiquantitatively assess in a standardized form, for the first time, changes in self-perception. Three treatment groups reflecting patients treated with various neurostimulating devices were studied and compared regarding possible changes in self-perception:

- A) DBS group: Patients treated with deep brain stimulation (DBS), which uses a central nervous implanted neurostimulating device directly connected to the brain [23]; DBS is used for therapeutic purposes in a growing number of diseases [9,24,25]. It is well-established for effectively treating PD and epilepsy [1,2].
- B) iVNS group: Patients treated with implanted vagus nerve stimulation (iVNS), i.e., a “peripheral” implanted neurostimulating device connected to the brain via the vagus nerve [26]; iVNS is used for the treatment of epilepsy, and less frequently for the treatment of depression [27].
- C) TC group: Patients treated with transcutaneous vagus nerve stimulation (tVNS) or electrical trigeminal nerve stimulation (eTNS), which transcutaneously apply stimuli to the brain via the vagus/trigeminal nerve; tVNS and eTNS are used for the treatment of epilepsy and will be lumped together in the transcutaneous group (TC group) for the purpose of this study [28,29].

The here published first systematic assessment of the unwanted treatment effects of changes in self-perception was performed as a cross-sectional study using a newly developed questionnaire, the FST-questionnaire (*Fragebogen zur Veränderung der Selbstwahrnehmung unter tiefer Hirnstimulation*; *Questionnaire regarding changes in self-perception while treated with DBS*).

We proposed and studied the following hypotheses:

**Hypothesis 1 (H1).** Changes in self-perception can be detected and documented in patients following interventions with various neurostimulating devices using standardized assessment tools.

**Hypothesis 2 (H2).** Central nervous implanted neurostimulating devices (deep brain stimulation [DBS]) will have a greater impact on the patient's self-perception than “peripheral” implanted devices (implanted vagus nerve stimulation [iVNS]) and external devices (transcutaneous vagus nerve stimulation [tVNS] or transcutaneous electrical trigeminal nerve stimulation [eTNS]).

## 2. Methods

### 2.1. Self-perception as a basis for the FST-questionnaire

The FST-questionnaire was developed based on the theoretical construct “changes in self-perception” [30].

For the operationalization of this construct, we reviewed earlier qualitative publications reporting individual changes in patients' self-perception following interventions in the brain with neurostimulating devices [3,11,12,14,31–35]. All direct quotes from patients regarding such changes in their self-concept and the corresponding interpretations given by the authors were considered.

The construct “changes in self-perception” and the corresponding items of the FST-questionnaire were thereby solely derived from the self-perception of the patients and their view of their personality, life, and social world based on a narrative approach [36]. The described changes and their corresponding items were classified into two groups:

- 1) “Neutral changes”, including all changes in self-perception, in which it is not certain if these changes are considered positive, neutral, or negative by the patients, such as seeing the world with different

eyes (item 18) or being told to act differently since the intervention (item 42).

- 2) “Negative changes”, including all changes in self-perception that could be considered negative and hinting towards processes of self-alienation, such as not feeling fully responsible for one's action since the intervention (item 28), having concerns about becoming a machine (item 32), or having the impression that the device is influencing one's decisions (item 26) [37].

For a thorough discussion of all single items and their possible interpretations on the background of theoretical and philosophical constructs (subjective wellbeing, self-mechanization, self-alienation), we refer to reference [38].

### 2.2. The FST-questionnaire

The FST-questionnaire was developed for patients treated with implanted neurostimulating devices (FST-DBS and FST-iVNS; 44 items; German; see supplementary files) under the above assumptions [38]. It was adapted for patients treated with transcutaneous neurostimulating devices (FST-tVNS and FST-eTNS; 33 items; German; see supplementary files). Comparing all three postulated treatment groups (A–C) and focusing on the proposed hypotheses, this paper will report on 26 items (6 *global* items [4 binary items; 2 multiple-choice items] and 20 *specific* items, see below), which could be answered by all three treatment groups.

### 2.3. Global items and attribution groups

The 6 *global* items focused on general thoughts about the device used and the patient's life. These items were recorded on a binary level or through multiple-choice questions. **Table 1** shows *global* items (*binary global* items: 2, 3, 5, 6 and *multiple-choice global* items: 9, 10).

Considering the variety of possible attributions of stimulation targets regarding item 10, two attribution groups were defined for patients of all treatment groups:

- I) “Soma group”: patients who believe that the device is solely connected to/stimulating the body and/or brain.
- II) “Psyche group”: patients who believe that the corresponding device is at least connected to/stimulating one psychological domain (soul, spirit, ego, self, consciousness, identity, personality).

### 2.4. Specific items and CHANGE/NEG scores

Twenty *specific* items focused explicitly on the operationalized construct “changes in self-perception”. They recorded the responses on the same 5-point Likert scale (endpoints: 0 = never/do not agree; 4 = very often/absolutely agree). Items 25 and 44 (marked **bold** in **Table 3**) are

**Table 1**  
Global items (binary and multiple choice) used in the FST-questionnaire (English translation).

Global items	
Item 2	I would choose the used neurostimulatory treatment option again. ( <i>binary</i> )
Item 3	The neurostimulator has changed my life. ( <i>binary</i> )
Item 5	The neurostimulator has changed the view about my own body. ( <i>binary</i> )
Item 6	The neurostimulator has changed my personality. ( <i>binary</i> )
Item 9	About the neurostimulator know... ( <i>multiple choice</i> ) a) my friends; b) my colleagues; c) my family; d) most fellow men; e) my partner
Item 10	The neurostimulator is connected to and/or stimulating my/location of my... ( <i>multiple choice</i> ) a) body; b) brain; c) soul; d) spirit; e) ego; f) self; g) consciousness; h) identity; i) personality

**Table 2**

Specific items representing “neutral changes” used in the FST-questionnaire, FST-DBS Version (English translation).

Specific items representing “neutral changes” (5-point Likert scale)	
Item 18	Since the implantation of the neurostimulator, I see the world with different eyes.
Item 19	Since the implantation of the neurostimulator, my view regarding myself has changed.
Item 20	Since the implantation of the neurostimulator, my interests and hobbies have changed.
Item 21	Since the implantation of the neurostimulator, my goals in life have changed.
Item 22	Since the implantation of the neurostimulator, my beliefs and expectations have changed.
Item 23	Since the implantation of the neurostimulator, my general mood has changed.
Item 24	Since the implantation of the neurostimulator, my way of behaving has changed.
Item 29	Since the implantation of the neurostimulator, I do many daily things in a different manner.
Item 36	I think about the neurostimulator.
Item 37	I talk with others about the neurostimulator.
Item 38	I have to explain to others how the neurostimulator is working.
Item 41	Since the implantation of the neurostimulator, people tell me that I have changed.
Item 42	Since the implantation of the neurostimulator, people tell me that I act differently than before.

**inverted** items, which means that responses close to the “endpoint 0 = never/do not agree” are considered tending towards “changes in self-perception”. Specific items representing changes that could be seen as positive, neutral, or negative changes by the patients (See Section 2.1, “neutral changes”) are displayed in Table 2.

Specific items hinting towards processes of self-alienation (See Section 2.1, “negative changes”) are displayed in Table 3. Inverted items are marked **bold**.

The calculated CHANGE score and NEG score (see below) were used as overall measures for the unwanted treatment effect of (*self-alienating*) changes in self-perception following interventions in the brain [39].

The CHANGE score contained all specific items focused on changes in self-perception irrespective of their assessment through the patients as positive, neutral, or negative changes (“neutral changes” and “negative changes”). The CHANGE score contained therefore all 20 specific items (possible range 0 to 80).

The NEG score focused on purely negative connoted items which may indicate processes of self-alienation (“negative changes”; Items 25–28; 32, 43, 44). The NEG score contained all 7 specific items, which assessed *self-alienating* changes in self-perception (possible range 0 to 28).

## 2.5. Patients

Fifty patients were included in the single-center, cross-sectional pilot-study: 24 DBS patients, 15 iVNS patients, and 11 transcutaneously treated patients (7 tVNS and 4 eTNS patients). Out of the DBS patients,

**Table 3**

Specific items representing “negative changes” marked \*n used in the FST-questionnaire, FST-DBS Version (English translation). Inverted items are marked **bold**.

Specific items representing “negative changes” (5-point Likert scale)	
<b>Item 25*n</b>	<b>I still perceive my actions as my own.</b>
Item 26*n	I have the feeling that the neurostimulator is influencing my decisions.
Item 27*n	Since the implantation of the neurostimulator, I feel less present/involved in my actions.
Item 28*n	Since the implantation of the neurostimulator, I do not feel fully responsible for my behavior and actions anymore.
Item 32*n	I ask myself if I am becoming a machine through the neurostimulator.
Item 43*n	My surrounding is calling me a cyborg/machine/robot.
<b>Item 44*n</b>	<b>After the implantation of the neurostimulator, I could easily return to my normal life.</b>

**Table 4**

Patient variables for all three treatment groups regarding age, sex, and time since intervention. N: number of patients.

Patient variables			
Treatment group (N)	age (years) mean (range)	sex (N) male/female	time since intervention (month) mean (range)
DBS patients (24)	59.8 (32–80)	14/10	68.8 (9–144)
iVNS patients (15)	42.3 (24–78)	6/9	67.9 (12–180)
TC patients (11)	38.6 (19–51)	2/9	3.7 (2–6)

21 were suffering from PD, and all other patients suffered from epilepsy. All participants were patients treated in the Department of Stereotactic and Functional Neurosurgery or in the Department of Epileptology at the University Hospital in Freiburg, Germany, and were recruited between June 2013 and September 2015. The study was approved by the ethics committee of the University of Freiburg in May 2013. All patients gave written informed consent for their participation in the study. Inclusion criteria were either PD or epilepsy and treatment with one of the specified neurostimulating devices more than two months prior to the survey. Table 4 shows patient variables.

## 2.6. Statistical methods

The results of the questionnaires were analyzed descriptively (H1). Statistical analyses comparing treatment groups (H2) – regarding single items and scores – were performed based on Fisher-Exact test for binary data, *t*-tests for interval-scaled data ( $\alpha = 0.05$ ), and Spearman's rho for rank correlation using SPSS 22.

## 3. Results

### 3.1. Global items of the FST-questionnaire

Global items focused on general thoughts about the device used and its general impact on the patient's life. Eighty-three percent of the DBS patients, 73% of the iVNS patients, and 64% of the TC patients would choose their treatment-option again (item 2). Eighty-seven percent of the DBS patients, 73% of the iVNS patients, and 67% of the TC patients considered that their life had changed through the treatment (item 3). Twenty-two percent of the DBS patients, 33% of the iVNS patients, and 18% of the TC patients considered that their personality had changed through the treatment (item 6).

The *t*-test indicated no significant differences between treatment groups (A–C) for binary items.

Asked for their personal view regarding what their neurostimulating device was stimulating/connected to, patients offered a variety of answers (Table 5, item 10).

From the DBS patients, 11 out of 24 belonged to the defined psyche group (i.e., believed that the device was at least connected to/stimulating one psychological domain), from the iVNS patients three out of 15 and from the TC patients two out of 10 (one TC patient did not answer item 10) belonged to the psyche group.

### 3.2. Specific items of the FST-questionnaire

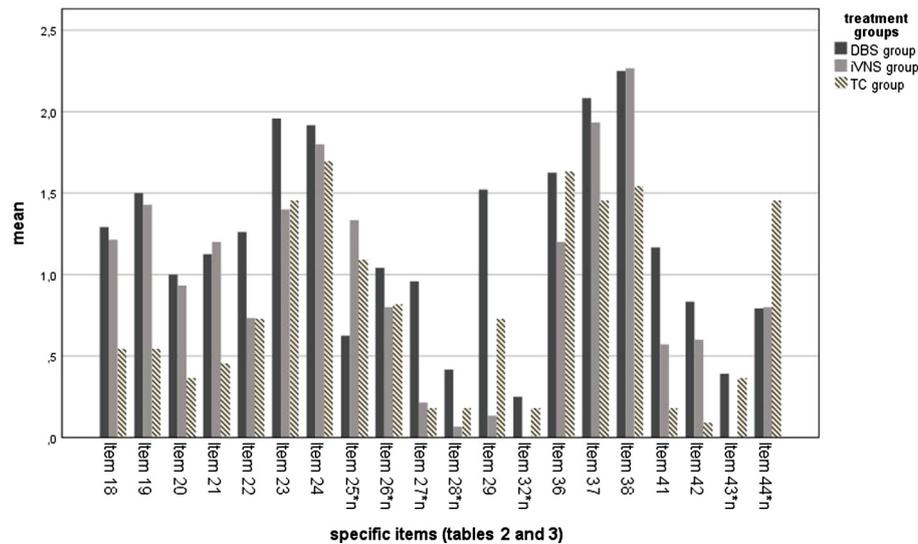
Specific items focused explicitly on the operationalized construct “changes in self-perception”. All responses to specific items were recorded on 5-point Likert scales (endpoints: 0 = never/do not agree; 4 = very often/absolutely agree). Fig. 1 shows means for specific items.

### 3.3. CHANGE score and NEG score

In the CHANGE score as an overall assessment of changes in self-perception (containing all 20 specific items), DBS patients scored a

**Table 5**  
Multiple-choice item 10: patients reported their beliefs as to what the stimulator was connected to and/or stimulating (multiple answers possible).

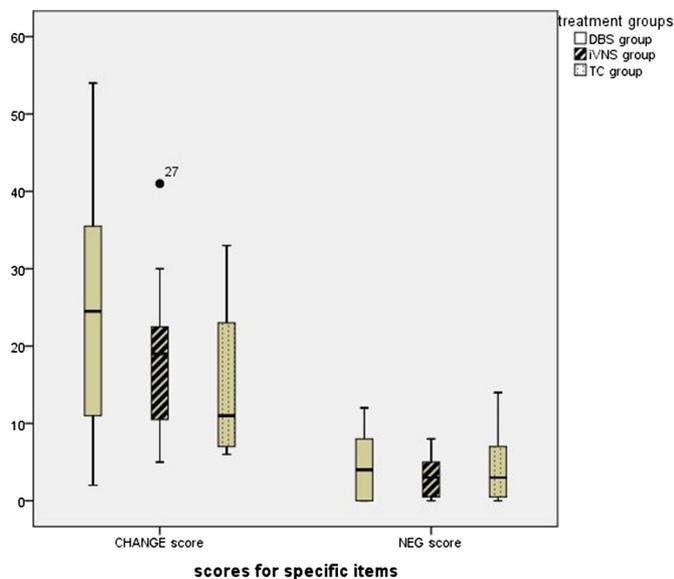
Item 10: The neurostimulator is connected to and/or stimulating my/location of my...	body	brain	soul	spirit	ego	self	consciousness	identity	personality
Treatment group (N)									
DBS patients (24)	75.0%	91.7%	4.2%	8.3%	8.3%	12.5%	29.2%	8.3%	29.2%
iVNS patients (15)	80.0%	73.3%	0.0%	0.0%	0.0%	0.0%	6.7%	0.0%	13.3%
TC patients (10)	10.0%	60.0%	10.0%	0.0%	0.0%	10.0%	20.0%	0.0%	10.0%



**Fig. 1.** Mean scores for specific items (5-point Likert scale) for patients in all three treatment groups. Items representing “negative changes” are marked “n”. For the description of the items see Tables 2 and 3.

mean of 23.9 (range: 2–54), iVNS patients scored 18.4 (range: 5–41) and TC patients 15.6 (range: 6–33). The *t*-test indicated no significant differences between all three treatment groups.

In the NEG score, DBS patients scored a mean of 4.5 (range: 0–12), iVNS patients scored 3.2 (range: 0–8), and TC patients 4.3 (range: 0–14). The *t*-test indicated no significant differences between all three treatment groups. Fig. 2 shows CHANGE scores and NEG scores for all treatment groups.



**Fig. 2.** Boxplots with median, interquartile range and range (27: spike of patient “27”) for CHANGE scores and NEG scores for all three treatment groups.

### 3.4. Patient variables and scores

In the CHANGE score, patients with PD ( $N = 21$ , mean: 25.86) scored significantly higher than patients with epilepsy ( $N = 29$ , mean: 16.45;  $p = 0.018$ ). For the CHANGE score, there was also a significant correlation between higher age and higher scores ( $\rho = 0.367$ ;  $p = 0.009$ ).

The *t*-test and Spearman's rho indicated no significant differences for the NEG score between patients with PD and patients with epilepsy or correlations between age and NEG scores. For both scores, *t*-tests indicated no significant differences between male and female patients.

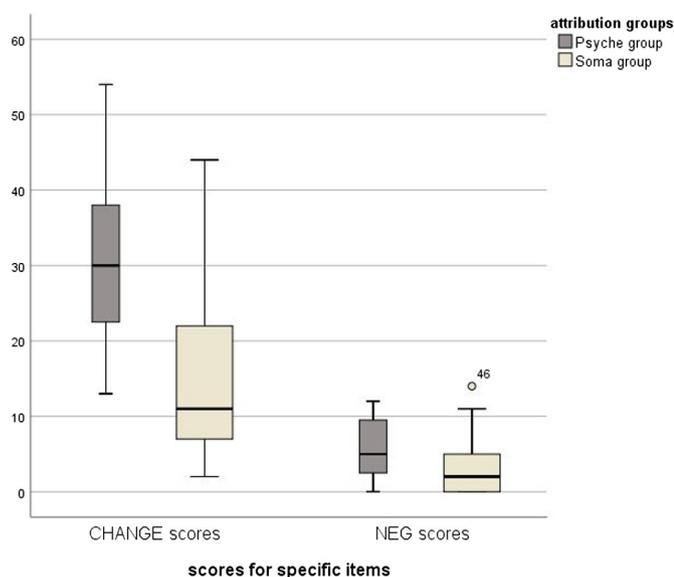
### 3.5. Attribution groups and scores

Analyzing the described attribution groups (psyche group and soma group; item 10) regarding CHANGE scores and NEG scores, *t*-tests indicated significant differences between the attribution groups. Patients belonging to the psyche group ( $N = 16$ ) had higher means than patients belonging to the soma group ( $N = 33$ ) for CHANGE scores (psyche group: 31.25, soma group: 15.24;  $p = 0.000$ ) and NEG scores (psyche group: 6.00, soma group: 3.03;  $p = 0.014$ ). Fig. 3 shows CHANGE scores and NEG scores for the two attribution groups.

Spearman's rho also showed a positive correlation for all 49 patients (one patient did not answer item 10) between the number of attributed psychological domains (possible range: 0–7) and the mean for CHANGE scores ( $\rho = 0.601$ ;  $p = 0.000$ ) and for NEG scores ( $\rho = 0.427$ ;  $p = 0.002$ ).

## 4. Discussion

To our knowledge, this is the first systematic semiquantitative assessment of the unwanted treatment effects of changes in self-perception following interventions in the brain using neurostimulating



**Fig. 3.** Boxplots with median, interquartile range and range (46: spike of patient “46”) for CHANGE scores and NEG scores for the two defined *attribution groups*, grouping patients depending on their view of what the corresponding device is connected to/stimulating (soma group and psyche group; See Section 2.3, item 10; Table 5).

devices. While there had been casuistic qualitative reports about those changes in individual patients suffering from PD undergoing treatment with DBS, we here introduce a new common assessment tool or questionnaire to detect and document these changes (semi)quantitatively on a group level and provide first cross-sectional pilot data.

The first finding in this study was that all treatment options were considered as overall positive interventions (item 2). Nevertheless, some patients saw changes in their lives (item 3) and their personality (item 6). These findings tend to resonate with the multiple individual qualitative findings of changes in self-perception following DBS [3,11,12,14,31].

Since all treatment groups had mean CHANGE scores of about 20 (possible range 0 to 80) as an overall measure for changes in self-perception, the authors consider that all treatment groups on average had – on a descriptive level – *moderate* changes in self-perception following interventions in the brain using neurostimulating devices. These findings confirm hypothesis H1.

These *moderate* changes in self-perception on a group level included patients who saw their goals in life (item 21), their beliefs (item 22), their general mood (item 23), and their way of behaving changed through the intervention (item 24) and noted that they often thought about (item 36) and talked about their treatment device.

In the analyses of the calculated CHANGE scores, there were differences between the DBS, the iVNS, and the TC group. As expected (H2) the mean CHANGE score of the DBS group was higher than the mean score of the iVNS and TC group. However, these differences between groups were not statistically significant. On average, *moderate* changes in self-perception were reported in all treatment groups, irrespectively of whether the neurostimulating devices were implanted or used transcutaneously or if they stimulated central nervous or more peripheral nervous structures (vagus nerve/trigeminal nerve).

Focusing on items that may indicate processes of self-alienation (“negative changes”), the NEG score was calculated. In the analyses of the calculated NEG scores, there were small differences between the DBS, the iVNS, and the TC group. As expected (H2) the mean NEG score of the DBS group was slightly higher than the mean score of the iVNS and TC group. However, these differences between groups were not statistically significant. Since all treatment groups had mean NEG scores of about 4 (possible range 0 to 28) as an overall measure for alarming *self-alienating* changes in self-perception, the authors consider

that all treatment groups on average had – on a descriptive level – *minor* self-alienating changes in self-perception following interventions in the brain using neurostimulating devices.

These *minor* self-alienating changes in self-perception on a group level included patients who did not conceive their actions as their own anymore (item 25), felt less present/involved in their actions (item 27), and/or were called cyborg/machine/robot by their surrounding (item 43).

This study is limited by its sample size, the pending construct validation, and by variable ages and durations of stimulation treatments in the three analyzed brain stimulation groups, reflecting the use of the techniques in clinical practice. Nevertheless, indicators of unwanted treatment effects of alterations in self-perception were found in all treatment groups during the process of neurostimulating interventions in the brain. While these *moderate* changes were not necessarily seen as negative, tendencies towards *minor self-alienating* changes in self-perception occurred.

Differences were found in the calculated scores on a group level between DBS treatment (implanted and central nervous), iVNS treatment (implanted and “peripheral”), and the tVNS and eTNS treatment (either not implanted but transcutaneously used and “peripheral”). The mean CHANGE and NEG score of the DBS group was higher than the mean score of the iVNS and the TC group. The limited patient numbers may have contributed to a lack of statistical significance of this finding supporting H2.

The similar distribution across the different stimulation approaches may furthermore suggest that effects on self-perception are not solely a consequence of neurobiological alterations but also related to patient beliefs, concepts, and stimulation attribution. Such beliefs were indicated in the notion of the patients that each treatment option, even the (from a medical viewpoint) more indirect ones like iVNS and especially tVNS and eTNS, were seen subjectively by some patients to interact with psychological domains like the self, the soul, the consciousness, and the personality (psyche group; item 10). In the statistical analysis, these patients had significantly higher CHANGE scores and NEG scores.

These stimulation attributions may explain in part why the patients felt changes in self-perception also as a consequence of more indirect and not implanted treatments. It seems that some patients had a body concept that differed from the medical one and which was oriented in a more holistic concept that could be addressed against the background of the phenomenological and anthropological distinction between “*Körper*” as a physiological entity and “*Leib*” as the sphere of subjective experiences [40]. The integration of both perspectives (“*Körper haben*” – “*Leib sein*”; *having a body* – *being a body*) is typical for a human being’s self-understanding.

## 5. Conclusions

Compared to published casuistic reports on changes in self-perception in individual patients, the application of the newly developed FST-questionnaire – as standardized assessment tool – opens up a new way beyond purely qualitative individual case descriptions in the analysis of how a wide spectrum of interventions in the brain using neurostimulating techniques can affect patients and their social lives through the challenging process of incorporating an electrical device into one’s body, brain, and self-image. Furthermore, the FST-questionnaire opens up the possibility to systematically assess the interaction between patients’ attributions of stimulation targets and (*self-alienating*) changes in self-perception in a standardized form. It may assist to identify the subgroup of patients at risk of experiencing treatment-emergent problems prior to the intervention.

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The study represents original research material. All authors listed on the manuscript have contributed sufficiently to the project and manuscript to be included as authors. Ethical approval was obtained.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2018.10.012>.

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