



Living with an intruder in the brain.
A phenomenological analysis of
patients' experience with Deep
Brain Stimulation

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What is a phenomenological interview?

Main features a of phenomenological interview:

- has its roots in phenomenological tradition
- it is focused on a specific personal experience
- it aims to bring out sensations, emotions and memories that are usually hidden
- it tries to define the structure of the experience
- it is focused on qualitative data of the experience

Characteristics of the sample

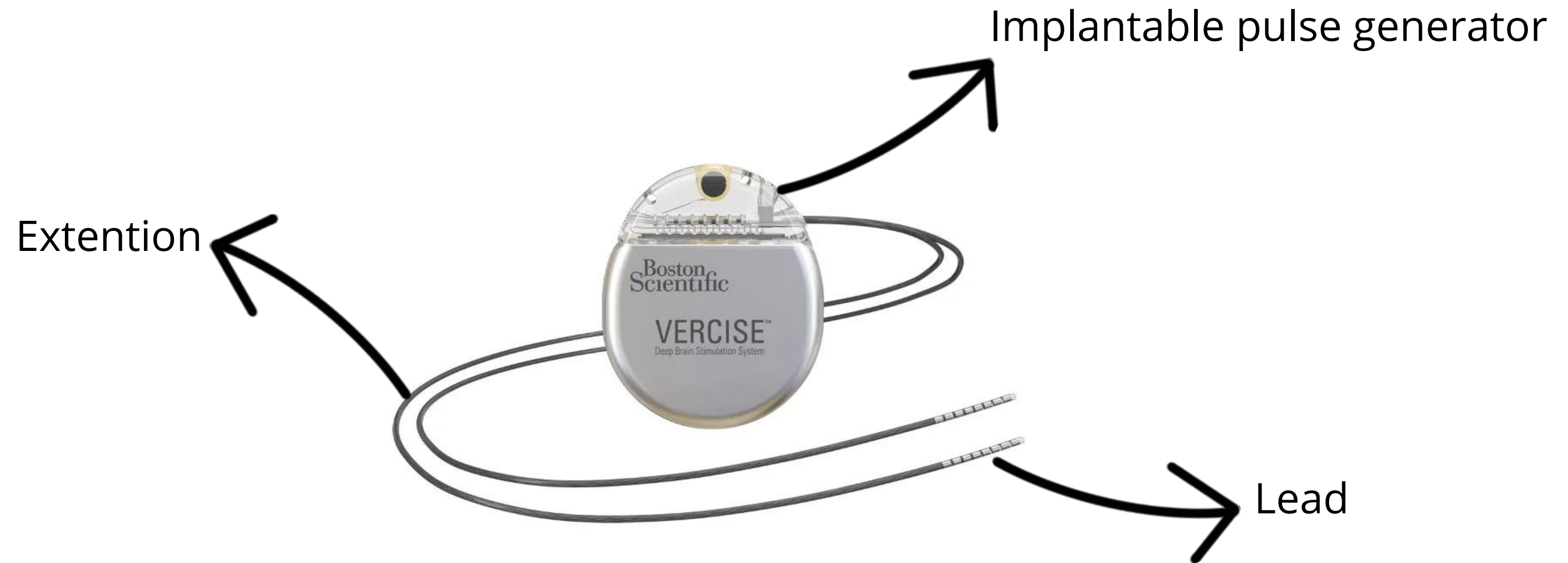
- total number of patients interviewed: 9
- sex of patients: 6 women and 3 men
- average age: 55 years
- Nationality of patients: 8 Italians and 1 Swiss
- patients' mother tongue: Italian
- patients' disease: 8 Parkinson's disease and 1 parkinsonism

Deep Brain Stimulation

Deep Brain Stimulation (DBS) is a neurosurgical procedure that uses implanted electrodes to treat movement disorders associated with Parkinson's disease, essential tremor and other neurological conditions. It fits the interests of this research for two reasons:

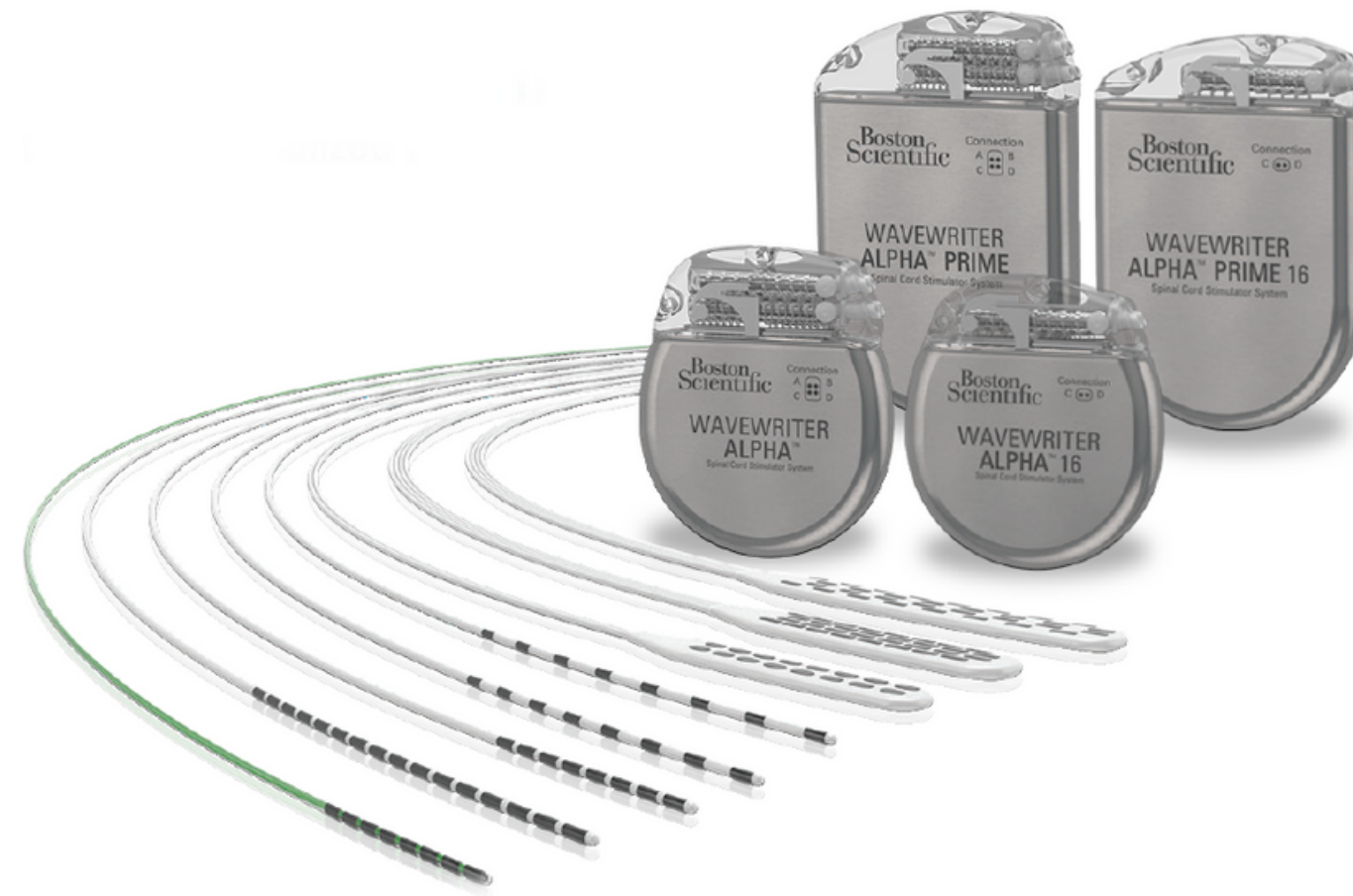
- 1) it is the most widespread brain-computer interface in the world
- 2) it is an invasive procedure and this allows us to study a deep interaction between human and machine

Deep Brain Stimulation

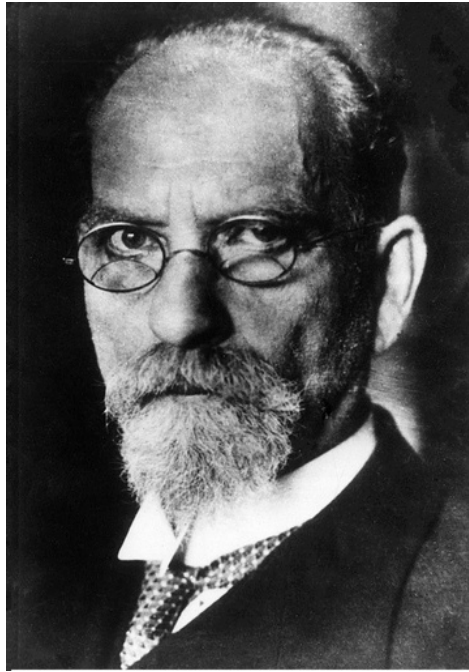


Phenomenology of Deep Brain Stimulation

From a phenomenological point of view Deep Brain Stimulation 1) is a machine 2) with a medical purpose 3) that is both an organ and a mere object at the same time.



Phenomenological considerations on our way of living



Husserl identifies two different dimension in human being: a physical one and a psychological one. These two dimensions are strictly connected to each other and inseparable. Thanks to this union we have a peculiar access to the phenomenal world.

Merleau-Ponty remarks the immediacy of our perceptions due to the combination of the psychological and the physical spheres. We are not only our mental or bodily impressions but a sum of the two. In fact, we instantly translate our mental states in a psychical states and vice versa.

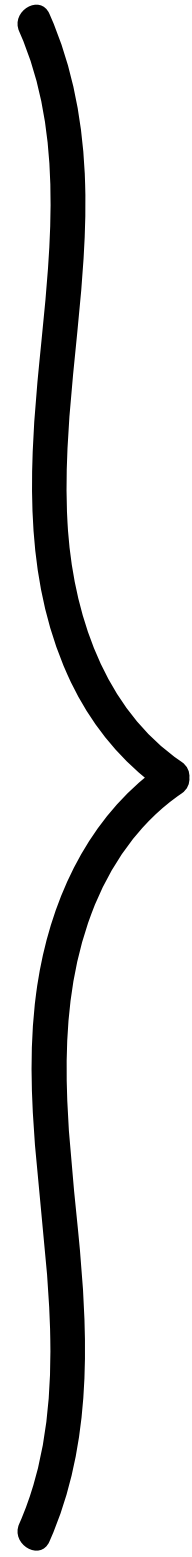


Analysis of side effects

Interviewer: "Do you think DBS interact directly on your psychological side, bodily side or both?"

Patient 9: "For me both, because if I feel good physically I feel good psychologically as well."

Patient 6: "In my opinion there is a direct effect due to the device, and then there is an induced effect: if you are not getting the results you expected, you are feeling a bit depressed."



Coherent translation of physical impressions in psychological states: intact mind-body bound

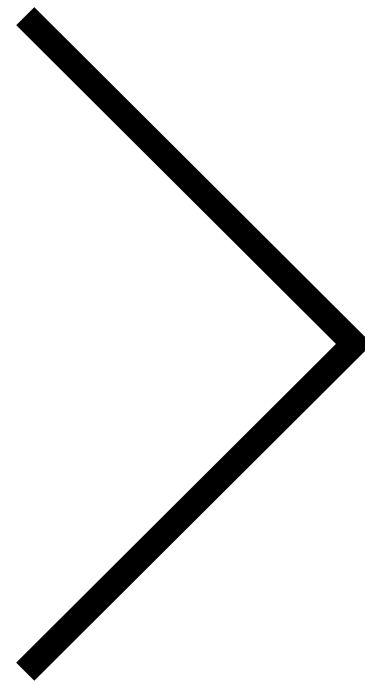
Analysis of side effects: the case of patient 4

Interviewer: "Do you feel normal since using DBS?"

Patient 4: "Yes... I mean, almost normal, because sometime my hand still shakes, even though it shakes in a imperceptible way."

Intervirwer: "How do you rate DBS in terms of general benefits?"

Patient 4: "I'd say 9 out of 10. Very positive for me."



Interviewer: "How do you feel psychologically?"

Patient 4: "I'm out of sorts. I am not the same person anymore... I feel depressed."



Analysis of the "flat condition"

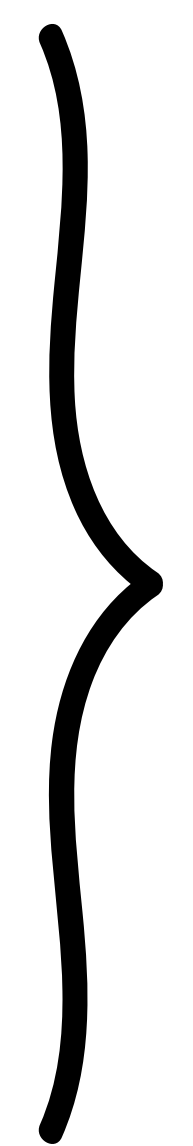
Interviewer: "Do you perceive DBS like a part of you or like something that is separate from you?"

Patient 2: "Usually I don't notice it. It's a part of me. I'm fine with it."

Patient 8: "It's a part of me now... it does not bother me."

Patient 3: " I know DBS helps me to live better, and that's enough. I usually forget to have two electrodes in the brain."

Patient 7: "I don't have any physical feedback that suggests me the device is active. My life is going on as normally."



This return to normality is experienced as a return to the human condition that had been lost due to Parkinson's disease.

Analysis of new aspects resulting from human-machine synthesis

Patient 2: "We'll see for how long *I'll turn myself off.*"

Patient 7: "*I was turned off* one single time to learn how to use the remote control."



Patient 9: "The other day *I had to switch myself off* while I was in the operating room."

Patient 6: "I hope, even when *I am on*, to be able to have these kinds of experiences."

Analysis of new aspects resulting from human-machine synthesis

"Turn on" and "turn off" are ways of being of machines. We can not turn off or turn on a biological body



But if we turn off DBS we shut down the entire body of a patient



The bound between mind and body can be turn off and turn on, and with it the whole experience of living like a human: the patient is thus a human and a machine in the same time

Thanks for your attention!

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