Mind Control? Fear and Media Portrayal of 'Brain Pacemakers'

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There's more to Fear than Fear Itself:

Fears and Anxieties in the 21st Century

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Oonagh Hayes

Abstract
Commonly called a 'brain pacemaker', Deep Brain Stimulation (DBS) is a type of therapy involving the surgical implantation of a device into the brain. Research findings on DBS frequently find their way into the media. In the media, scientific information is often 'translated' so as to become accessible to lay people. Scientists must expect emotional reactions when delivering their work to a lay public. In the case of health issues, fear is certainly one of the foremost reactions. Precise fears and overall anxieties may also shape the way information is understood and contribute to the forming of opinions. These opinions might be relevant to decisions about oneself, one's body or the general orientation of medical research; therefore, having an impact on medical policies themselves. This chapter will highlight what types of fear are expressed in relation to neuromodulation and which function they fulfil. Beyond poor quality journalism aiming for sensation and beyond fear-induced conservative stances, fear may be of relevance in the cognitive apprehension of complex scientific data. Based on the case of DBS, this chapter will tackle questions such as: Can fear of medical research and care be considered in ways other than legitimate or irrational? What role does fear play in processing elaborate information? To what extent can lay people's fear have a constructive impact on a scientific field?

Key Words: Deep brain stimulation, neuromodulation, media, knowledge transfer, medicine, communication, expert, lay person, ethics.

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1. Introduction

This chapter is about fear in representations of Deep Brain Stimulation (DSB) in the mainstream media. It forms parts of a broader research project about DBS and the transfer of knowledge in German speaking countries.

> Like him, 250.000 people in Germany suffer from this shattering disease [Parkinson's Disease]. More than 30.000 of them have had a brain pacemaker implanted until now. For what sounds like a *horror film* has turned into reality since the beginning of the nineties.[1]

Although the rest of this newspaper article about Deep Brain Stimulation does not make particular use of fear inducing images, inserting a reference to horror films without apparent reason presupposes an array of available associations for the readers. Why the focus on fear? Although it is not the prevalent emotion in news coverage of

DBS, it is nevertheless present and striking: fear leaves a powerful impression and has lasting effects, and is, therefore, worthy of careful attention. Some information about DBS will be necessary to understand its representations.

Broadly speaking, modern DBS was invented in 1987.[2] The breakthrough occurred when modulation replaced lesion for treatment of the motor symptoms of Parkinson's disease. Chronically implanted 'brain pacemakers' then started to be considered as a serious alternative to brain lesion and were soon recognised for a number of neurological conditions and psychiatric conditions.[3] DBS is based on a neurosurgical procedure to implant electrodes in the brain. The stimulation alters brain activity in order to improve symptoms; however, it is not curative.[4] As a neurosurgical intervention, it has long been considered as a last resort: i.e. for treatment-resistant conditions or when drugs wear off or side-effects become unbearable, as with L-dopa for Parkinson's.[5] An interdisciplinary team decides on patients who should receive DBS so as to minimise physical and psychological risks, foremost suicide.[6] The team often consists of the attending neurologist, a neurosurgeon, a psychiatrist and an ethicist. By the end of 2014, estimations suggest 100,000 patients were living with a DBS-device worldwide.[7]

Two remarks to conclude about DBS as a technique: First, DBS was applied to motor symptoms and was then extended to psychiatric symptoms.[8] It is also interesting to observe that DBS is reversible. For most treated conditions, DBS replaced lesion as a last resort. The brain areas are broadly the same, both interventions are based on the same knowledge of brain functions, but DBS has the advantages of reversibility and adaptation of parameters according to the evolution of the patient's condition.[9]

2. Threat to Personality and Change in Personality: A Narrative between Medical Treatment and Social Conventions, A Historical Comparison

The history of neurosurgery – in particular, the infamous chapter of its history relating to psychosurgery, i.e. lobotomy for psychiatric conditions – is prominent in the scientific discourse about DBS, as well as in media discourses about DBS.[10] This has an undeniable impact on the handling of ethical issues concerning DBS. Ethical safeguarding is central in discourses about DBS to ensure that DBS will not be rejected by patients all together merely out of fear of a repetition of history or its associations with psychosurgery. The reversibility of the therapy is emphasised in order to distinguish DBS from its historical precursor.

Whereas there is an acute awareness of the issue of a potential change in personality involved in neuromodulation, the historical antecedents and the broader cultural framework surrounding and shaping this concern do not seem to attract much attention.[11] Here there is neither a significant transposition nor even an awareness of the historical (and contemporary) context and influence on medical practices of cultural ways of thinking, or 'thought styles'.[12] A historical case and case reports

about gambling under DBS, for instance, underline moral aspects in the neurological narrative.

The famous case of Phineas Gage offers an enlightening example. In 1848, on a construction site, an iron rod was blasted clear through the head of a 25-year-old worker. The iron rod was over three feet long, a quarter of an inch in diameter, more than 13 pounds heavy and landed some 80 feet away, damaging a considerable portion of the man's left frontal lobe on its way.[13] He not only survived but went on to live 13 more years before eventually succumbing to the consequences of his condition.[14] Popular reports often depict Gage as a hard-working, pleasant man prior to the accident.[15] Post-accident, he is stereotypically described as a changed man, suggesting that the injury had transformed him into a surly, aggressive drunkard who was unable to hold down a job. The myths surrounding the effects of Gage's injury seem to have grown after his death, and many of these claims are not supported by any direct evidence from primary sources. There is no first hand evidence for this long-term change in personality.[16] The only precise account is that of the physician who attended him in the time of his recovery immediately following the accident:

> He is *fitful, irreverent, indulging at times in the grossest profanity* (which was not previously his custom), manifesting but little deference for his fellows, impatient of restraint or advice when it conflicts with his *desires*, at times pertinaciously *obstinate*, yet *capricious* and *vacillating*, devising many plans of future operations, which are no sooner arranged than they are abandoned in turn for others appearing more feasible. A child in his intellectual capacity and manifestations, he has the *animal passions* of a strong man. Previous to his injury […] he possessed a well-balanced mind, and was looked upon by those who knew him as a *shrewd, smart businessman*, very energetic and *persistent* in executing all his plans of operation. In this regard his mind was radically changed, so decidedly that his friends and acquaintances said he was "no longer Gage".[17]

It is now widely accepted that the focus on social and moral changes in his character were exaggerated. The last significant publication on the subject asserts that the stories about Gage's dramatic shift in personality are largely the stuff of legend.[18] It must be noted, however, that they correspond to contemporaneous expectations and constructions of morality as well as to social conventions, in particular binaries such as: civilised vs. primitive, control vs. passion and desire, and, interestingly enough, persistence vs. instability – here referring to his moods but also his job situation, which has since been refuted by historical evidence.

What does this early and spectacular event in the history of neurology tell us today? In the first decade of the 21st century, many medical publications focused on

the potential side effects of DBS. These potential side effects were relayed in sensationalised ways in mainstream press, as showed in the very end of an article published in a widespread weekly periodical:

> Neuro-implants are a challenge for the sense of personal identity: Members of an ethics committee had to rack their brains about the *tragic* case of a Dutch Parkinson's patient. Due to his DBS-therapy, the 62-year-old became manic and *financially ruined* himself within three years through *uninhibited expenditures*. Eventually, he was admitted to a psychiatric clinic. His mania was unequivocally linked to the electrical stimulation. Without it, the man was *reasonable* and *judicious*, but bed-ridden because of his affection. "There were only two alternatives: a nursing home (without stimulation) or stationary psychiatry (with stimulation)" reports Sabine Müller in an article for the journal "Neuroethik und Neuropsychologie". The stimulation was interrupted and the patient asked what he wanted. He opted for DBS – and with it for the placement in a psychiatric facility.[19]

Fears and anxieties about DBS and changes to personality tend to focus on the risk of pathological gambling after DBS: surgery, compulsive shopping or eating, addiction; but also explosive-aggressive behaviour, mania and hyper-sexuality.[20] These are obviously socially deviant behaviours and are treated as such in the press, as well as pathologised by the medical research staff. Other conditions mentioned are 'apathy, hallucinations and depression, but also *inadequately* high spirits, hyper-sexuality, voyeurism, *extravagant* material prodigality, *carelessness*, cleptomania and even the *loss of moral ability to judge*'.[21]

The moral aspect of the behaviours depicted and the potential interference of the therapy with a presumed natural state of being or with assumed natural morality strongly depend on social and cultural constructions of natural and moral behaviour. They are based on notions of positively connoted unaltered nature as well as the moral maturity of humankind, as in this extract:

> For some of the patients, turning on the electrodes made them fall from 4 to 2 on the Kohlberg scale.[22] They lost *their moral competence literally at the push of a button* and from a moral point of view went from the stage of an adult to that of a young child.[23]

Interestingly, one study also engages with euphoria, defining 'how happy is too happy'[24] from an ethical point of view when medically modulating brain activities.

Notwithstanding medical evidence and legal definitions, we cannot ignore the moral aspects of the observed changes. The medication is adjusted so as to suppress

these arguably socially deviant behaviours. The ethical problem regards the change induced by turning on a device, that is to say a change with exogenous – and technological – causes.[25] In the case descriptions, the focus is set on the supposed inadequacy of the effects, or when the effects are not considered normal behaviour. They implicitly refer to a supposed normal set of behaviours and, in doing so, reinforce what is considered normal and normative behaviour.

Whereas a century and a half after Phineas Gage's accident the role of the historical context in the representations of his change in personality eventually became apparent to historians of medicine, the contemporary cultural context is rarely recognised or perceived as shaping or even influencing current medical or popular representations of pathological behaviours at all either in relation to DBS or more broadly.

3. Fear, Uncertainty and Trustworthiness of the Men in White Lab Coats

Uncertainties around how DBS works are central to the fears and anxieties that surround it. One is based on the fact that to this day the therapeutical effects of DBS can be observed but not explained, as it is put on the website of the US-National *Institute of Mental Health* for a general public:

> Although it is unclear exactly how the device works […], scientists believe that the pulses help to 'reset' the area of the brain that is malfunctioning so that it works normally again.[26]

Likewise, a neurosurgical publication states: 'The discovery of techniques and brain targets have been serendipitous, as the fundamental mechanism of the therapeutic effects of DBS remains unclear'.[27] A medical-political report affirms: 'The exact mechanism of DBS action is unknown, but it remains a viable treatment option for certain disorders'.[28] For the same condition, different brain targets can be considered for stimulation: for example, for patients with Parkinson's disease, two locations are both considered suitable for stimulation: the subthalamic nucleus (STN) and the globus pallidus interna (Gpi).[29]

This expression of uncertainty can be perceived as honesty: saying as much as is known and no more means that what is published is trustworthy. Yet, on the other hand, uncertainty can also be understood as missing proof and missing competence, as in the following abstract:

> Mechanism of action unknown. The complex interactions of the different "centres" of the brain cannot by all means and not for a long time yet be understood nor even purposefully manipulated by electric shocks. Neurosurgeons laconically reported in an article in the 'Deutschen Ärzteblatt'[30] of 2010 that "good results" had been obtained in treating obsessive-compulsive disorders "even when the

> position of the electrodes quite varied" – although completely different brain areas had been stimulated! It's the same with DBS for depression: three different research centres are working on three different brain areas […] but the stimulation shows the same results everywhere. [Two project leaders] presume that it could be due to the fact that these three areas are linked by the medial forebrain bundle.[31]

The subjunctive in the German original text puts a distance between enunciation and message, expresses more than a doubt but instead downright scepticism. The reference to three different stimulations with 'the same results' implies a degree of nearly unprofessional imprecision regarding the application of the therapy. The empirical work in medical research is perceived as threatening. The general tone of the article sheds an altogether negative light on DBS. While the formulations are still subtle in this extract stressing uncertainty, they are less so in other passages of the article.

Does complexity fuel fear? Do issues that elude the broad public due to their degree of complexity bear a potential threat? If these issues are perceived as relevant to oneself, one's body, one's immediate environment, relatives and/or community, or seen as an imperative global political issue, then the gap between the need to know and the incapacity to understand could well cause fear. Accordingly, if fear is caused by uncertainty, do hard facts confer the impression of more control and less fear? Making science accessible to the broad public has been a growing concern for research groups conscious of the impact of public opinion on their image and, hence, in the long term, on their funding.

4. Concluding Remarks: Fear in Representations of DBS

While fear can be a negative emotion if it were to lead to a total rejection of DBS, fear in its media portrayal also fulfils different functions. Fear laden discussion about DBS still draws attention to the subject, expands willingness to confront a complex topic and take time to engage with it or to deal actively with it. Fear can prompt a defence against a threat: the historical example of psychosurgery shows that lasting concerns about patients' well-being serve as an ethical safeguard for DBS, making sure DBS will not be rejected altogether but recognised for its own merits. Fear accompanies today's research and care as a condition of their sustainability; fear, to some extent, means public awareness and engagement.

Expressions of fear are culturally conditioned and, therefore, can be identified and analysed as such. Discourse analysis gives an indication about the society in which particular discourses arise: i.e. societies' constructions of norms and deviations. The concerns about morality and the fear of a degenerating civilisation in the 19th century have been replaced in the neo-liberal 21st century, focused on its own image of what the supposed good individual is, does and does not do. Discourse analysis discloses

less about the object of the discourse than about the subjects forming the discourse. DBS is particularly interesting in that respect because it associates brain, thoughts and personality, all existential topics, with medical interventions (therapy), concepts of self, and hopes for the future both of medicine and of humankind.

Notes

[1] Juliane Simon, 'Fernbedienung fürs Gehirn', *Die Tageszeitung* (German daily newspaper), 15 August 2009, 15. My translation and emphasis.
[2] Alim-Louis Benabid, et al., 'Combined (Thalamotomy and Stimulation) Stereotactic Surgery of the VIM Thalamic Nucleus for Bilateral Parkinson Disease', *Applied Neurophysiology* 50.16 (1987): 344-46.
[3] Alim-Louis Benabid, 'Deep Brain Stimulation for Parkinson's Disease', *Current Opinion in Neurobiology* 13.6 (2003): 696-706.
[4] Rüdiger Hilker et al., 'Disease Progression Continues in Patients with Advanced Parkinson's Disease and Effective Subthalamic Nucleus Stimulation', *Journal of Neurology, Neurosurgery, and Psychiatry* 76.9 (2005): 1217-21.
[5] Deep-Brain Stimulation for Parkinson's Disease Study Group, 'Deep-Brain Stimulation of the Subthalamic Nucleus or the Pars Interna of the Globus Pallidus in Parkinson's Disease', *The New England Journal of Medicine* 345.13 (2001): 956-63.
[6] Tobias Skuban et al., 'Psychiatrische Nebenwirkungen der Tiefen Hirnstimulation bei idiopathischem Parkinsonsyndrom' (Psychiatric Side Effects of Deep Brain Stimulation in Parkinson's Disease) *Fortschritte der Neurologie Psychiatrie* 79.12 (2011): 703-10.
[7] Andres M. Lozano and Nir Lipsman, 'Probing and Regulating Dysfunctional Circuits Using Deep Brain Stimulation', *Neuron* 77.3 (2013): 406-24.
[8] Helen S. Mayberg et al., 'Deep Brain Stimulation for Treatment-Resistant Depression', *Neuron* 45.5 (2005): 651-60.
[9] Thomas E. Schlaepfer and Klaus Lieb, 'Deep Brain Stimulation for Treatment of Refractory Depression', *The Lancet* 366.9495 (2005): 1420-22.
[10] Amy Gutmann for the US-Presidential Commission for the Study of Bioethical Issues, 'Deep Brain Stimulation Research and the Ethically Difficult History of Psychosurgery', *Gray Matters, Integrative Approaches for the Neuroscience, Ethics and Society Volume 1*, viewed 16 September 2015, http://www.bioethics.gov/sites/default/files/Gray%20Matters%20Vol%201.pdf.
[11] Arne Manzeschke and Michael Zichy, eds. *Therapie und Person. Ethische und anthropologische Aspekte der tiefen Hirnstimulation* (Münster: Mentis, 2013).
[12] Concept by Ludwik Fleck in his book *Entstehung und Entwicklung einer wissenschaftlichen Tatsache, Einführung in die Lehre vom Denkstil und Denkkollektiv* (Basel: Frankfurt am Main, 1980), 129-145.

[13] John M. Harlow, 'Passage of an Iron Rod through the Head', *Boston Medical and Surgical Journal* 39.20 (1848): 389-93.
[14] Fred G. Barker, 'Phineas among the Phrenologists: The American Crowbar Case and Nineteenth-Century Theories of Cerebral Localization', *Journal of Neurosurgery* 82.4 (1995): 672-82.
[15] Malcolm Macmillan, *An Odd Kind of Fame: Stories of Phineas Gage* (Massachusetts: MIT Press, 2002).
[16] Neither Harlow (the physician who published on Gage's injuries) nor any others who had actual contact with Gage reported any of these behaviours: Kendra Cherry, 'Phineas Gage, An Astonishing Case of Brain Injury', *Psychology*, viewed 16 September 2015, http://psychology.about.com/od/historyofpsychology/a/phineas-gage.htm.
[17] Harlow, 'Recovery from the Passage of an Iron Bar through the Head', *Publications of the Massachusetts Medical Society* 2 (1868): 327-347; Reprinted in *History of Psychiatry* 4.14 (1993): 328. Emphasis added.
[18] Macmillan, *An Odd Kind of Fame.*
[19] Matthias Becker, 'Risiko Neuroimplantate', *Spiegel*, 6 June 2012, viewed on 16 September 2015, http://www.spiegel.de/gesundheit/diagnose/risiko-neuroimplantate-mediziner-wagen-gehirnoperationen-an-wachen-patienten-a-836030.html.
[20] Polyvios Demetriades, Hugh Rickards, and Andrea Eugenio Cavanna, 'Impulse Control Disorders Following Deep Brain Stimulation of the Subthalamic Nucleus in Parkinson's Disease: Clinical Aspects', *Parkinson's Disease* (2011): 1-9, Viewed 16 September 2015, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3043299/.
[21] Institut Technik – Theologie – Naturwissenschaften of the LMU Munich, Objectives of the working sessions on ethical, legal and social questions in the field of life sciences, programme 'Therapy and Person. The Philosophical Problem of Personal Identity and the Consequences of Neurological Therapies Based on the Example of Deep Brain Stimulation', viewed 16 September 2015, http://www.ttn-institut.de/sites/www.ttn-institut.de/files/Projektbeschreibung%20Therapie%20und%20Person_0.pdf.
My translation. Emphasis added.
[22] Named after Lawrence Kohlberg, cf. his theory of stages of moral development.
[23] Sabine Müller, 'Minimal-Invasive und nanoskalige Therapien von Gehirnerkrankungen: eine medizinethische Diskussion', *Nanotechnologien im Kontext. Philosophische, ethische und gesellschaftliche Perspektiven,* eds. Alfred Nordmann, Joachim Schummer, Astrid Schwarz (Berlin: Akad, 2006), 345-370. My translation. Emphasis added.

[24] Matthis Synofzik, Thomas E. Schlaepfer, and Joseph J. Fins, 'How Happy Is Too Happy? Euphoria, Neuroethics, and Deep Brain Stimulation of the Nucleus Accumbens', *AJOB Neuroscience* 3.1 (2012): 30-36.
[25] Incidentally, change in personality is a given aspect with a chronic disease, whatever the nature of its causes.
[26] 'Brain Stimulation Therapies', *National Institute of Mental Health*, viewed 16 September 2015, http://www.nimh.nih.gov/health/topics/brain-stimulation-therapies/brain-stimulation-therapies.shtml.
[27] M. A. Liker et al., 'Deep Brain Stimulation: An Evolving Technology', *Proceedings of the IEEE* 96.7 (July 2008): 1129-41, here 1129.
[28] Amy Gutmann, 'For the US-Presidential Commission for the Study of Bioethical Issues', *Gray Matters, Topics at the Intersection of Neuroscience, Ethics and Society* 2, viewed 16 September 2015, http://bioethics.gov/sites/default/files/GrayMatter_V2_508.pdf, 37.
[29] Frances M. Weaver, 'Randomized Trial of Deep Brain Stimulation for Parkinson Disease: Thirty-Six-Month Outcomes', *Neurology* 79.1 (2012): 55-65.
[30] The 'Deutschen Ärzteblatt' is a weekly magazine addressed to medical doctors, published by the German Medical Association (Bundesärztekammer/ Arbeitsgemeinschaft der deutschen Ärztekammern) and the National Association of Statutory Health Insurance Physicians (Kassenärztliche Bundesvereinigung).
[31] Becker, 'Risiko Neuroimplantate', *Spiegel*.

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