



The Phenomenon of Brain World Neuroculture in the Making by Patients with Parkinson's Disease

By Markus Idvall

Abstract

The aim of this article is to explore how the phenomenon of brain world, as a symptom of a possible emerging neuroculture, is perceived and enacted by patients with Parkinson's disease, who, in their daily life, are subjected to neuroscience, most often as chronically ill individuals hoping for a cure, but also in some instances as participants in clinical trials. The article is based on a multifaceted ethnographic material that maps the experiences of biomedical research among patients with Parkinson's. The main body of material consists of interviews carried out in 2012 and 2015, and comprises 19 transcripts of recorded conversations, conducted in groups as well as individually. The article argues that the exposure of the patients to clinical neuroscience gives birth to neuroculture. A materialist-discursive phenomenon called brain world—perceptions and enactments of the brain—is problematized on the basis of how patients cope with and reflect on their chronic illness in everyday life situations and in confrontation with clinical neuroscience. The embodied experience of the illness operates as the route into the brain world and also becomes the ground for how this world is featured with specific properties. Brain world is in this respect a contradictory entity: both plastic and fragile, both accessible and too complex, both strange and known. Most of all, brain world, in the eyes of the patients, relates to a territory still dominated by neuroscientists.

Keywords: Brain world, neuroculture, patient perspective, Parkinson's disease.

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Introduction

It is a dream: to repair a human brain by injecting new cells. In theory, this treatment could cure Alzheimer's, stroke, Parkinson's and other diseases that develop when brain cells die.

In practice, realising the dream starts with work on Parkinson's disease. This is because other neurological illnesses are more complicated, biologically speaking. They affect many different types of cell scattered throughout the nervous system. Parkinson's, on the other hand, mainly attacks one type of cell found in a specific area of the brain. This is why Parkinson's has become something of a test case; it is the most obvious choice of brain disease for trying out a cure with a dose of new cells (Snaprud 2014: 70).

In an article of the Swedish popular science magazine *Forskning & Framsteg*, readers are invited to take a peek into the mysterious world of the brain. A new kind of research into cell transplants aimed at curing Parkinson's disease is presented. Scientists are working with different types of cell: cells from aborted human fetuses and various types of stem cell. The potential future experimental treatment with what are labelled as "induced pluripotent stem cells" (iPS) is illustrated across one page. The computer-generated image shows how skin cells will be taken from a patient. These are transformed into dopamine-producing cells and reintroduced into the patient through brain implantation. The illustration allows us to look into the patient's brain ("look into" with some reservations, since the illustrated brain is a dark and profoundly unidentified area here). We are shown the location of the implant by a cross in the exposed part of the brain. The graphics designer has chosen to write the name of this part: "Basal ganglia". This is the place from which the implanted stem cells—the new agents—will start branching out to replace the neurons that originally released the dopamine now lacking in the patient's brain and body.

Forskning & Framsteg is a great example of how new goals and findings in scientific research are illustrated in popular science (see e.g. Ideland 2002). The magazine opens a window on worlds that are otherwise hidden or inaccessible in people's daily lives. The above example is about the unknown life of the brain. The approach is similar to the way media, a few decades ago, exposed their audience to the inner world of the human body. One of the pioneers was the social anthropologist Emily Martin (1994), who in the 1990s analyzed how scientific knowledge about the body's immune system spread to, and was interpreted by, different sectors of society and popular culture. In a similar way, the inner world of the head—the brain—is now emerging and being explained in different societal

contexts. New neuroscientific knowledge about the brain is picked up and used in social, economic and political settings.¹ A multitude of sites and agents in the brain is becoming visible. These sites and agents may be microscopic discoveries, but have epistemological and ontological consequences for people. Together they constitute a brain world and, so to speak, a new part of the human body, and—in extension—a new part of society at large. The basal ganglia, popularized by Parkinson's researchers, is only one of many examples of how different sites and agents in the brain appear in the wake of biomedical research and take on an increasingly important role in societal discussions and contexts related to fighting chronic diseases, improving public health and increasing people's individual capacity.

How important is the development of this new brain world in society as a whole? Is it valid, as some scholars claim, to speak about the emergence of a neuroculture that is transforming our relationship to ourselves, our relationships to who we are and the sort of lives we live? Is there an “emerging neuro-ontology”, as suggested by the sociologist Nikolas Rose and the historian of science Joelle M. Abi-Rached, based on a “somatic ethic gradually extending from the body to the embodied mind—the brain” (2013: 22)? Is neuroscience's understanding of the brain becoming a part of how we approach and live our day-to-day life?

The aim of this article is to explore how the phenomenon of the brain world, as a possible symptom of an emerging neuroculture, is perceived and enacted by patients with Parkinson's disease. The patients in their daily life are subjected to various forms of neuroscience (cell transplants, genetics, growth factors, etc.), most often as chronically ill individuals hoping for a cure, but also in some instances as participants in clinical trials. This article focuses on the “materialist-discursive [...] performativity” of how these patients relate to the type of expertise matters that they encounter and that they, through their illness and their position as patients, also embody. Within this materialist framing of what neuroculture may be, I refer to the gender scholar Victoria Pitts-Taylor's expression “complexly embrained embodiment” as a foundation for understanding how culture is shaped by “entanglement[s] of matter, measure, and meaning” (2016: 10, 31, italics in original). The material reality that exists in the fact that the individuals are treated for their illness and thereby exposed to different kinds of biomedical intervention (diagnosis, treatments, pharmaceuticals, experiments) is mutually co-productive with the symbols and interpretations that the individuals live by when enduring their disease. A phenomenon such as the brain world thus imposes what Pitts-Taylor calls, “an onto-epistemological approach, one that takes questions of being and knowing as inseparable” (2016: 20).

The results presented here come from an interview study with Parkinson's patients in which the idea of a brain world appeared as an additional topic. The

interviews were intended to deal with issues of informed consent and patient power in connection with clinical trials. However, the idea of a brain world was so important that it supplanted to some extent the pre-established topics of discussion that were focused on patient information, consent procedures and medical staff-patient relationships, in care and clinical trials.

The discussion below starts with a brief description of the fieldwork. Thereafter, focus is directed onto how accounts by the patients of the loss of dopamine in the brain become a material route into the brain world. I then explore how the individuals relate to this new, strange world. On the one hand, it is a world that belongs to—and is contingent on the experiences of—the patients. On the other hand, this world's visibility and accessibility depends heavily on medical expertise and technology. Finally, the possible significance of the concept of “neuroculture” is presented, and how it is linked to the phenomenon of the brain world.

Material and Methods

This article is based on a multifaceted ethnographic material that reflects the experiences of biomedical research among patients and research subjects. The main body of the material consists of interviews carried out in 2012 and 2015, and comprises 19 transcripts of recorded conversations, some of which were conducted in groups while others were conducted individually. In total, 32 persons with Parkinson's disease participated in the conversations. The participants were from 35 to 80 years old and included both men and women. The majority were men in their 50s and 60s.

The group conversations took place in focus groups. They were carried out in 2012 within the framework of a multidisciplinary research project called TRANSEURO.² Three focus groups, each consisting of 5-6 participants, of Parkinson's patients were formed to discuss the topic of experimental medical treatments.³

The individual interviews with Parkinson's patients were conducted in 2015 within a project in the research environment BAGADILICO.⁴ Sixteen people were interviewed about their experiences in taking part in clinical trials within Parkinson's research. Relatives of the patients also participated in eight of the interviews.⁵

This article is based also on material from a handful of observations made in my subjects' own environments. Further, it draws on books and articles in which people with Parkinson's describe their experiences of the illness and of medical research.

The Route into the Brain World

The materialist-discursive route into the brain world of Parkinson's patients is founded on current biomedical explanatory models, which were established in the 1950s and 60s through scientific research in Sweden and Austria (Palfreman 2015:26-28). The current theory of how Parkinson's develops is based on the role of dopamine deficiency. When the neurons that release dopamine in a healthy brain die for some reason, dopamine in the brain becomes deficient, and the various symptoms of Parkinson's disease—rigidity, tremor, freezing—develop (Hagell 2004: 78-79).

The route of Parkinson's patients into the brain world starts when they embody the biomedical explanatory model that identifies a lack of dopamine in the brain as the cause of the disease. The route of patients differs from that of medical experts (doctors, scientists). The patients may focus on dopamine, but transform the explanatory model into an entity other than the conventional diagnosis model—an entity that is vaguer and more individual than the original medical model. According to how medical anthropologist Arthur Kleinman (1980) has described how ill individuals cope with disease, a lay explanatory model forms the basis of how individual Parkinson's patients interpret their illness, while they allow dopamine (or rather the lack of dopamine) to become a guide into the brain world. In the illness explanations adopted by Parkinson's patients, the brain world emerges as a critical inner area for the disease. When these individuals learn that the origin of their illness and somatic symptoms is situated in the brain, the fleshy organ becomes a complexly embrained embodiment, subject to different types of interpretation and understanding: it becomes a materialist-discursive brain world (Pitts-Taylor 2016: 10).

The onset of Parkinson's, which is so crucial for the route into the brain world, is often described as gradual and insidious. Patients frequently refer to a specific day on which the diagnosis was given, but suggest that they had probably been ill for a long time without knowing it. There had been signs that something was wrong. A twitching finger or a leg that felt weak. In retrospect, this can be traced to the progressive death of nerve cells. In line with this, a woman who was diagnosed when she was in her 40s and had felt signs even earlier, explained that the symptoms did not become noticeable until, according to her calculations, 50 per cent of the neurons that release dopamine had disappeared. Another woman, who was in her 50s at the time of the interview, and who had been diagnosed a few years earlier, considered whether she could herself have caused the successive disappearance of nerve cells through her lifestyle. She told me that she was hooked on "kicks" even as a child. For example, she loved going on rollercoasters. And as an adult, she still has an attraction for kicks. After the diagnosis, she wondered whether this obsession has tired the brain and driven the cells away.

As a consequence of these queries, she is now trying to live in a way that does not exhaust the brain. At her place of work, for example, she does not want to learn the new business system that her employer is introducing. Learning a new system would be too big a strain on the brain, she says. In her view it might accelerate the progression of the disease.

A drug against Parkinson's was developed in the 1960s, following the discovery of dopamine a few years earlier. Levodopa, or L-dopa, as this new medicine was called, turned out to be an effective treatment that compensates for the lack of dopamine and alleviates the motor symptoms (Hagell 2004:79). L-dopa revolutionized the lives of patients. Suddenly, it was possible to treat severely ill patients. However, it was soon discovered that L-dopa is associated with a number of side-effects and complications for Parkinson's patients. In particular, the medication causes what are known as "dyskinesias" or "hypermobility" in many patients. In his book *Brain Storms*, Parkinson's patient and journalist Jon Palfreman summarizes the breakthrough period with L-dopa as follows:

While L-dopa was vastly superior to what came before, the drug fell far short of being a cure. On the one hand, the L-dopa allowed "frozen" wheelchair-bound individuals to walk again and increased patients' life expectancy. On the other hand, virtually all patients taking levodopa were sentenced to future disabling motor complications (Palfreman 2015: 33).

For people with Parkinson's, the brain world is not just the area in which the disease originates. It is also a reception and target area for the various agents that are going to replace the lost dopamine. In this role, the brain world is an uncertain and diffuse environment for the patient. None of the dopamine replacements are ideal, and the uncertainty surrounding the replacement of dopamine becomes a central part of how patients experience their own situation. One man, who had sat silent during much of his focus group, suddenly said that the medication had affected him so strongly that he had had periods with such horrific nightmares that he fell out of bed. Another man, who had lived with his illness for around ten years, revealed in an individual interview that the medication had caused him to become addicted to computer games for some time. He managed his work, but spent all his waking hours at home playing. This resulted in a broken marriage. At the time of the interview, he was still heavily medicated, but he was happy that he had managed to stop taking the drug that had changed his personality.

The brain world of the patients is also reflected in their striving to find new ways of feeling better through new medication. An alternative to L-dopa for a patient with recent onset are the agents known as "dopamine agonists". Their effects

on the Parkinson's symptoms are less than the effect of L-dopa, but they are often used when a patient experiences motor problems. The biological mechanism of these agonists differs from those of other medications. While L-dopa, for example, is converted to dopamine after entering the brain, the agonists activate receptors in the brain that produce dopamine.⁶ One interviewee, who had been prescribed this medicine, explained that the agonists take a different path than dopamine in the brain—they take what she called “shortcuts”. Jon Palfreman describes the agonists as follows:

They pass freely through the blood-brain barrier and actually trick the receptors in the striatum [a part of the cerebrum] into action. While the brain isn't actually receiving dopamine, it “thinks” it is and reacts accordingly (Palfreman 2015: 33).

The route into the brain world often starts with an understanding of the brain as a malleable organ. This plasticity corresponds with the neuroscientific view of the brain (cf. Doidge 2007). Accounts by patients of how they handle illness are colored by an imaginary world in which the brain is believed to be what Rose and Abi-Rached call “a site of choice, prudence, and responsibility for each individual” (2013:52). “Exercise improves the grey matter”, says one interviewee, who has started a training group that meets several times a week. The interviewee's explanation for this initiative is that exercise, in this case aerobics, significantly increases the blood supply to the brain. The assumed benefit from an active lifestyle is that one can free oneself from the drugs that have proved to have many side-effects after long-term use. Boxing as an antidote to excessive medication is another form of training mentioned by Parkinson's patients during the fieldwork. One man, who was diagnosed in his 40s, has been boxing several times a week for the past few years. He describes how his use of medication has been significantly reduced since he started training. He is now working actively to promote this particular form of training to other people with Parkinson's in Sweden.

Ironically, boxing has been linked to neurological disease, and is one of the sports that neuroscientists have warned against in the Swedish public debate (see e.g. *Aftonbladet*, 16 June, 2013). The legendary boxer Muhammad Ali (1942-2016) suffered from a type of Parkinson's and serves as a warning example for how damaging boxing can be to the brain. When people with Parkinson's box as a form of exercise, however, no punches to the head are allowed.

A World with Specific Properties

The anatomy of the brain has been more or less known since the mid-19th century, when neuroscience defined various regions of the brain and contributed to their mapping and characterization (Rose & Abi-Rached 2013: 62-63). Parkinson's patients sometimes use scientifically-based terms such as "Broca's area" or the "thalamus", but more often describe the brain as something strange and yet also a part of oneself. A woman of around 75 years of age, who was diagnosed with Parkinson's when she retired and is now beginning to feel limited by the disease, considers the brain to be a "mystery", and like "another planet".

Irrespective of the words they use, Parkinson's patients describe the brain as a relatively fragile and delicate world (They are joined in this opinion by the neuroscientists who oppose boxing). The aforementioned man, for example, who gathers his Parkinson's friends for training, supposes that "if something is injected into the head, it will affect both this and that". Another of my interviewees—a woman who has lived with Parkinson's for more than twenty years and who would personally be very hesitant to take part in invasive brain research such as cell transplants—associates brain surgery with "rooting around" in the brain. In other words, she considers the brain to be a fragile world, where researchers dig around during their operations. The brain seems to be a vulnerable area, which must be protected from too much interference, as there is a risk that the changes that follow surgery are too great. One interviewee illustrated the risks involved with brain surgery by telling me about two persons who had undergone the same type of operation, deep brain stimulation. This treatment involves electrodes being inserted into the brain to stimulate activity in specific sites, and to counteract the hypermobility associated with Parkinson's. My interviewee, who suffers from a relatively mild variant of the disease and who was not personally interested in any form of extensive surgery, told me that one of the two patients became well, whereas the other suffered a brain hemorrhage. Further, another of the interviewees emphasized the difficulty of finding the correct site for intervention in the brain. He participates in clinical research and says he does not believe it is possible to operate on the brain without affecting or disturbing its environment. The brain world is thus an interconnected territory in which every intervention, despite all possible precautions, has an effect in some direction or to some degree. From the perspective of the interviewee who participates in clinical trials, the effect on the brain can be both diffuse and unpredictable. Therefore, the interviewed man claimed that researchers who study consciousness and thoughts—psychologists—are needed in addition to researchers who investigate the physical brain—neurologists—when carrying out research projects that involve invasive procedures.

The fact that the brain is subjected to surgical procedures despite it being so vulnerable leads to a certain fascination among Parkinson's patients regarding interventions such as cell transplants. One patient whom I interviewed, who was

not himself a research subject at the time, took an interest in clinical trials. He said that he had recently seen an operation involving a brain cell transplant on television. He told how “they went in with a large needle into the brain and found the exact site where the cells were to be placed”. To him, this was the opposite of “rooting and digging” in the brain, as the operation was carried out with ultimate precision, skill and decisiveness in a fragile and vulnerable environment.

The brain world of Parkinson’s patients is not only vulnerable and fascinating, but also constitutes a container for different sorts of “gear” that may help the body in its movements. This becomes evident when talking about the type of operation mentioned above—deep brain stimulation (DBS). The operation involves implanting what is known as a “neurostimulator” together with electrodes into the brain. A battery under the skin supplies power for the system, which sends electrical impulses to the brain from the implanted neurostimulator. The aim of the treatment is to free Parkinson’s patients from their hypermobility. This is exactly what one of the interviewees experienced after her DBS operation. Before the treatment, she had severe problems with involuntary movements. People stared at her in public places, which caused her suffering. The operation made a great change in her life. The DBS implant supplies her brain with impulses, and gives her a concrete somatic experience. The fact that the DBS system can be switched off brings home even more intensely the feeling that the fully furnished brain, rather than the uncharged empty one, is the best friend of a body that moves normally. The interviewee has a folder at home with data about how the DBS system that she has implanted in her brain works and which settings have been made. She takes the folder with her every time she visits her neurologist, as if to show both herself and the doctor how her body’s normal function depends on the brain being fully charged and equipped.

Images of one’s own brain also create tangibility and a type of access into the brain. A handful of the interviewees have participated in invasive brain research related to cell transplants. One male research participant, who was later allocated to a randomized control trial, remembered that he had to do something with a joystick while lying in the MRI scanner⁷ so that the researchers could “measure different movements in the brain”. He added jokingly: “If you fall asleep during the scan, the result will be a bit strange”.

The brain world thus appears to Parkinson’s patients as something real. It is neuroculture in the making. But, what are the consequences of this neurocultural phenomenon for how these individuals relate to science and scientists? The next section discusses this question.

Privileged Territory for Researchers

The concept of the brain world is a form of lay knowledge about the brain among patients, and it seems that the more informed patients are about their illness, the more they can interact on equal terms with their healthcare provider. This corresponds to an ambition within the healthcare system for greater patient participation in patient-provider interaction both in Sweden and elsewhere. This ambition, however, is not as strong in the interviewees when it comes to their role in neuroscience. Several of them distance themselves from the idea that research subjects can form a partnership with scientists in the same way that patients act together with doctors and nurses in determining the course of treatment. Interventions in the brain are linked to possessing and managing certain knowledge—scientific knowledge about the brain—that the interviewees say they lack. This, therefore, automatically reduces their possibilities of participation on equal terms.

The brain is described as utterly complex by my interviewees, which is compatible with the lack of ambition described above. In the words of one of them, what the brain does—to provide a location for the embodiment of mind— makes it “cleverer than computers”. The complexity with which the brain is associated becomes an obstacle for the way in which the interviewees approach science. In their eyes, the brain is a world that is not fully accessible for anyone who lacks the scientific expertise required to understand it. In essence, it seems that the brain is too complicated for people in general to comprehend. The brain becomes instead the privileged territory of researchers. The brain world, in contrast, appears to be more accessible, since it is the negotiated contact surface that patients can use in their encounters with research (and the healthcare system).

Thus, most of the Parkinson’s patients who were interviewed did not believe in equality between researchers and patients. One woman explained, both with gestures and words, that research is “up here, and we are down there”. Another interviewee said that “brain research is too technical”, a sentiment with which her husband agreed. As non-specialists, this couple felt that they were completely in the hands of doctors and researchers. If they were to try to contribute something to brain research, it would inevitably be just a “superficial opinion”. Therefore, they did not believe in patient participation within research: “It is too specialized, and at a level that is unknown to us”.

Some interviewees even believed that greater patient participation within neuroscience is not a goal to strive towards since this kind of development would be unsafe for the performance of research. These individuals felt that limiting the researcher’s control by patient participation would pose a risk for how science can be productive.

However, some dissenting voices were heard. One of them belonged to an individual who is known for doing research within the Parkinson's field. This person has also participated in medical research projects both as an expert and as a research subject. However, none of these projects involved invasive brain research such as cell transplants. In the person's own words, it was what is seen as "less sexy" research that focuses on how to live with the disease rather than how to find a cure for it, which is assumed to be the goal of cell transplantation research. Paradoxically, this example illustrates how inaccessible brain research is for Parkinson's patients, even for those with a relatively good insight into the field. The brain that is "agentic" (Pitts-Taylor 2016: 60) in its complex materiality and biology demands that interventional operations of any kind must be made at micro-levels. These levels are invisible and inaccessible for people in general, but not for scientists who handle the technology and hold the knowledge that enables them to intervene into this materiality.

The Brain as Cultural Imaginary

The concept of neuroculture has been launched by several scholars who have pointed to the growing strength of neuroscience in recent years and how an increasing fascination and focus on the brain as a part of society has emerged at the same time (Vidal 2009; Rose & Abi-Rached 2013). It is, however, not clear what will be included in the concept of neuroculture. Will it be about increased general awareness of the brain's function and significance? Is it about a new type of cultural practice emerging among different groups and interests in society? Is it a new way of approaching issues of health, lifestyle and identity? Or is it about further aspects that we cannot yet grasp?

In this article, I have given some examples of how Parkinson's patients talk about processes and changes in their own bodies, which they link to the brain. I suggest that the embodied perspective of the brain that is articulated by the Parkinson's patients is an example of how neuroculture is emerging in society. This culture is materially anchored and symbolically shaped by complexly embodied individuals in different contexts. It is hierarchically stratified and constituted, in the sense that the interviewees regarded the researchers as the primary brain experts and interpreters, while they played down their own competence and significance in the field. At the same time, the patients' accounts contain a map of different sites, routes and agents in the brain—a world that enables the brain to emerge as more accessible and visible than ever before. Ideas about dopamine were the route into this brain world for people suffering from Parkinson's disease. Discussions about the lack of dopamine triggered awareness about the various mechanisms and properties of the brain. The patients referred to what is both

fictional and true; to a brain world that concurrently represents strangeness, vulnerability, fragility, electricity, accessibility, and complexity.

The accounts given by patients thus contribute to a neuroculture by becoming building blocks in a new cultural imaginary, where the brain—its materiality, structure, function, significance and ethic—is in focus. Whether this new movement can be used as an empowering tool in society and in research remains to be seen.

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Notes

¹ For an overview of this development, see e.g. Rose & Abi-Rached 2013, Pitts-Taylor 2016 and Hansson & Idvall 2017.

² TRANSEURO, standing for “Neural Transplantation in the Treatment of Patients with Parkinson's Disease”, started in 2010 and was set for realizing a small number of clinical trials with neural cell transplantations originally in England, Sweden and Germany. TRANSEURO is still active and is mainly a biomedical program (see www.transeuro.org.uk, 5 January 2018), but has also involved for some time a group of social and cultural scientists focused on issues of ethical governance (Idvall 2017b: 130-132).

³ The TRANSEURO study, moreover, included three focus groups consisting of relatives and non-affected individuals representing the views of the public. The focus group study has been discussed in two publications (Idvall, Wiszmeg & Lundin 2013; Idvall 2017b).

⁴ BAGADILICO, or “Basal Ganglia Disorders Linnaeus Consortium”, is a cross-disciplinary research environment at Lund University focused on biomedical investigations of Parkinson's disease and Huntington's disease. It was formed in 2008 and includes a cultural scientific group, which has published three central books (Liljefors, Lundin & Wiszmeg 2012; Hagen 2013; Hansson & Idvall 2017; see also www.med.lu.se/bagadilico, 5 January 2018). My own participation in this cultural scientific group was based on a three-year grant from the Swedish National Research Council (*Vetenskapsrådet*), 2014-2016.

⁵ Preliminary results relating to Parkinson's patients' tendency to synchronise their own time with that of research and thereby, if appropriate, accept recruitment to the studies, are found in Idvall (2017a, 2017c).

⁶ https://en.wikipedia.org/wiki/Dopamine_agonist, 2018-02-22.

⁷ MRI, or “magnetic resonance imaging”, is a radiology-based medical technology that produces images of the inside of the body.

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