

The Concordant Space of Biomedical Science: How Individuals with Parkinson's Disease Synchronize themselves with Clinical Trials

Markus Idvall

Department of Arts and Cultural Sciences, Division of Ethnology, Lund University, Lund, Sweden

ABSTRACT

Parkinson's disease (PD) becomes more frequent as populations grow older in western countries. Levodopa exists as medication, but is connected with side-effects. In search for an alternative therapy, patients become agents in different ways. The role as participant in clinical trials, not least, is one of these possibilities for lay influence in scientific matters. In this presentation we ask how one, as patient, relates to clinical science. How does one move along towards what, on the basis of one's degenerative illness, one perceives as the progress of science? Individuals with PD are, in this sense, temporal beings in whatever they do or calculate in relation to science. This article, based on an ethnographic fieldwork within the frames of a biomedical research project on cell transplantations, explores two different concepts – concordance and synchronizing – in terms of their analytical potential for understanding how research patients participate in clinical trials.

Keywords: *concordance, synchronizing, Parkinson's disease, clinical trials, space, time, patient perspective*

Introduction

Parkinson's disease (PD) is a chronic disorder spread worldwide. Around 7 million people in the world live with PD¹. Traditionally the disease has been a condition associated with ageing and the elderly. However, it is not unusual with individuals who experience the onset of the disease already in their thirties and forties. PD is a brain disorder with severe and incapacitating somatic symptoms: tremor, rigid muscles, slowness, and impaired posture and balance. Also non-somatic symptoms such as depression and dementia are associated with the disorder. Besides this, Parkinson's disease is a highly degenerative or progressive condition. The first symptoms experienced by an individual may be quite mild, a trembling finger for example. But the disease gets worse and may eventually become a stigmatizing disability for the individual. The end stage of Parkinson's disease is feared by many. It can involve the inability to stand and walk as well as to take care of oneself.

There is no cure for Parkinson's disease, even though the disorder has been known for centuries. The first time it was described in a more systematic way was by the Brit-

ish doctor James Parkinson. This was in the beginning of the 19th century and the disease was at the time called 'shaking palsy'. The disease received its current name – Parkinson's disease – in the second half of the 19th century when the renowned French physician Jean-Martin Charcot proposed the new name¹. It is still not known what exactly causes the onset of the disease. However, in the mid-20th century it was discovered that PD is linked to the loss of dopamine-producing cells in the brain. This scientific discovery led to the development of the drug levodopa as an effective medication for the PD symptoms. Nonetheless, it has turned out that after some years of medication, levodopa has serious side-effects for the patient. These side-effects, such as involuntary movements of the body (dyskinesias), can be as bad and painful for the individual as the disorder itself.

Material and Methods

Today, there is active biomedical research on PD in many parts of the world and within many fields of research. One of these research fields concerns the trans-

plantation of dopamine-producing neuron cells and stem cells into the brain of the invalid patient. This field has expanded a great deal over some decades, ever since the first clinical trials were conducted in the second half of the 1980s². In present time, a number of different neuroscientific centers in Europe collaborate in order to realize new clinical trials with dopamine-producing cells, under the EU-funded programme TRANSEURO. This programme started in 2010 and, after several years of modifying the technology and selecting patients for the trials, a small number of transplantations have now been conducted with patients in different European countries.

In my own work as ethnologist, I have followed the expansion of this biomedical programme for some years. I have conducted observations in different settings and focus groups and held individual interviews with clinical scientists, medical staff, patients, family members and the public, in order to learn more about what characterizes clinical research in a context where scientists and patients interact^{2,3}. What kind of collaborations can be identified between different actors and interests? My aim is to explore the possibilities for a mutual partnership between patients and researchers and thereby establish a new conceptual space for how the two categories relate to each other.

Biomedical research is normally quite a hierarchical practice with only the researchers themselves as active agents, while patients, families and the public have often been seen more as objects or instruments for conducting science in different ways. However, in the last few years there have been an increasing number of studies within social sciences and the humanities, which in different ways challenge the dominance of the natural sciences by introducing a more participatory, inclusive as well as critical perspective on the issues^{4,5}. My own research is a part in this scholarly development.

Below, I will draw attention to two concepts which, in different ways, can sharpen an analysis of the type of participatory network that may be represented in clinical science. First, it is the spatial concept of concordance which highlights the relationship between research patients and clinical scientists as a possible partnership. Second, I will focus upon the concept of synchronizing, which refers to how affected individuals move along tactically in relation to how science, in parallel, moves into new stages and generates new expectations.

Discussion

Concordance, my first term here, has its conceptual background in a health care discourse around year 2000. In a recent review, the medical sociologist David Armstrong identifies the birth of the concept as a development of and movement away from the long-term, and often non-productive, discussion on whether patients comply or not in different clinical situations. When the term concordance was introduced this implied, Armstrong writes, 'a greater agreement between doctor and patient on the nature of the problem, the need for treatment and the most

appropriate medication'⁶. Armstrong continues: 'Default and non-compliance had indicated a failure of the patient; lack of concordance reflected [in contrast] a failure of the consultation, mostly through the physician not having elicited the true nature of the patient's problem [...] or the patient's real concerns'⁶. Concordance, in Armstrong's view, was thus meant to endorse »a form of open consultation that encouraged the patient[s] to express their true selves by verbalizing their inner life-worlds«⁶. Not all scholars have been as positive towards the concept as Armstrong appears to be in his article. Judy Z. Segal, with an interest in the history and theory of rhetoric, is for example more critical of the concept of concordance. In an article from 2007, she sees the concept as »a sham« and as »a strategy for compliance«⁷. Patients may be addressed as »partners«, but in reality this is, according to Segal, just another way of bringing the patients »into agreement with physicians' prescriptions«⁷.

Still, I adhere to the concept as I see two important cultural analytic aspects of concordance. First, the concept of concordance promotes, as Armstrong articulates, a new openness for how doctors and patients relate to each other. We could say that there is a new space for cultural creativity in a relationship which historically has been rather fixed and conformist. Second, the concept of concordance, if we follow Armstrong, also relates to a patient-centering perspective which de-centers the authority of the doctor (read: the clinical scientist)⁶. I believe this patient-empowering aspect of concordance is the most imperative of all.

The patient-centering of concordant space can in this respect be linked to a radical time perspective on how the patients relate to their encounter with the doctors and the researchers. On the basis of this time orientation, my second term will be synchronizing. This concept is my own invention and it stems from my reading of the sociologist Kathy Charmaz's book »*Good Days, Bad Days: The Self in Chronic Illness and Time*«, from 1991. Here she points at how individuals with different kinds of chronic diseases live their lives in a very time structured and time reflective way. She discusses how time experience is fundamental for how the chronically ill constitute their selves and how they organize and cope with their lives⁸.

This radical time perspective of the individual patients is a way for me to achieve patient-centering in my study on what research patients experience in clinical trials. It is a means for understanding how a certain form of agreement may arise in the relationship between patients and clinical scientists even though the experiences and interests of the two categories may vary greatly. Through looking at concord rather than conflict, I highlight how individuals time the tempo of their own embodied progression into the disease with the opportunity to take part in clinical trials. Individuals in this respect negotiate their own progress into the complex condition of the illness with how they experience the movement of science, whether it is experienced as slow or fast, certain or uncertain, et cetera. In my fieldwork I have encountered two discrete modes of synchronizing in relation to clinical trials in general, and

the cell transplant trials in particular: aligning and navigating.

Aligning means that one actively makes one's life parallel with the scientific trials. Annika, a key interview subject in my study, was in her early forties when she contracted PD. Initially, she was in a state of shock and alienation. She started to look for information about the disease on the internet, but felt depressed. She could not identify with the disease and other people with PD who, in her eyes, were all elderly. But after some time, she came in contact with individuals of her own age and who also suffered from the disease. She decided to become more active in the patients' organization. At that time, she went to a lecture about a forthcoming research project on cell transplantation. After the lecture, she confronted the speaker/researcher and asked if she could take part in the future trials. She saw this as a chance to test something different. She was aware that the specific cell material and the specific method to be used may not prove suitable for everyone. Still, she wanted to test this possibility before she had come too far in the progression of the disease.

Since then, more than five years have passed. Annika has taken part in the biomedical research project. First, she was in a large observation group with different patients. Then, she became part of a smaller group, where she underwent different kinds of tests. Her condition was measured and evaluated in various ways. Eventually, she was one of the individuals who were randomized into the transplant group. At the time of writing, she has recently been transplanted with experimental cells into her brain and will now be subjected to medical follow-up for a number of years.

In Annika's case, aligning is thus a form of synchronizing movement where accepting the conditions is central for how one times one's own life and self with the institutionalizing practices of science. Her example shows how aligning is a movement on several levels. It is a chronological movement. She feels that she has reached an age and knows that there will be not so many more opportunities. It is an embodied movement. She has progressed into the disease this far and feels that she cannot progress any more now before it is too late. And it is an imagination of how the significant Other – the scientists – moves. She believes that research is making progress right now and feels that she needs to keep up-to-date with this.

Navigating, the other form of synchronizing that I want to pinpoint, is in contrast to aligning a movement where one sometimes turns away from clinical science, but just momentarily or for a period of time. It is not rejecting science, for a turning down can be followed by aligning, depending on the movements of life (and science). Navigating is more about living with one's disease in transit, in relation to the movements of science. This synchronizing movement includes dis-matching from science, but also essential moments of matching oneself with these practices. In this case Magnus' story can be illustrative. Like Annika, he contracted PD in his early forties. To start with, he turned down a request from one of the nurses at the clinic. It was not a formal request. The nurse only

checked whether he had any interest in participating in clinical trials at all. However, he became more and more interested in the scientific alternative and after a popular lecture by a scientist on cell transplant research he, pretty much like Annika, confronted the lecturer afterwards and asked if there was any possibility of joining as a transplant participant. He gave the researcher his name, and after some time he was enrolled in the project. When a friend, who also has Parkinson, questioned his decision by asking how he could let them »juggle with your brain«, he concluded that this friend was ten years younger than himself. Magnus saw this trial participation as »my chance to get something which I believe in«.

However, his participation in the research project has not really corresponded to his expectations. Like Annika, he has undergone several tests over the years, but, unlike her, he was randomized into the control group whose members are not going to receive a transplant. This was a great disappointment for him, and consequently he deliberated on whether to withdraw from the project, something he was free to do according to the informed consent sheet he had signed at the start. Still, he decided to stay in the study since he realized that it was going to be difficult to replace him, and since he also was promised to take part in the new trials that were already planned after the present project was finished.

Navigating is similar to the cultural theorist Michel de Certeau's concept of tactic mobility. As a synchronizing movement, navigating takes the individual across that sort of, in de Certeau's words, »enemy territory« that science may represent for potential research patients⁹. Quite often, it is not an alternative for a sick individual to take part in clinical trials. But occasionally, it happens that one becomes interested in the possibility of making one's life parallel with the movement of science. In this instance, the sick individual may cross new boundaries and try contacting scientists in different ways.

Conclusion

Concordance and synchronizing – together these terms work for a different view on the almost archetypical relationships of doctors and patients on the one hand, and of scientists and lay people on the other – a new type of view where the »weaker« part of the involved protagonists is given more space and possible impact than before⁹. Patient expertise and lay knowledge are, from this viewpoint, two sides of the same coin, ethically and politically. However, in both cases there is bewilderment about, and even a resistance against, how far one can go in the very argument. Even though patients may be seen as experts on their own bodies, usually it is the doctor, not the patient, who is active and has special responsibility for the nature of the medical problems. And even though lay individuals may make important contributions to science, usually it is the scientist, not the lay individual, who performs the final analyzes and comes to the final conclusions. Therefore the figure of the participating research patient can be experienced as a challenge in many different respects.

Acknowledgements

The article is based on my work in the research project »The Two Horizons of Research: Cultural Analysis of How

Patients and Scientists Face Each Other in Clinical Trials within the Research on Parkinson's Disease«, which was funded by the Swedish Research Council (*Vetenskapsrådet*) 2014-2016.

REFERENCES

PALFREMAN J, Brain storms: The race to unlock the mysteries of Parkinson's Disease (Scientific American/Farrar, Straus & Giroux, New York, 2015). – 2. IDVALL M, Ethnologia Scandinavica, 47 (2017) 57. – 3. IDVALL M, WISZMEG A, LUNDIN S, Focus Group Conversations on Clinical Possibilities and Risks within Parkinson Research: A Swedish Case Study (Department of Arts and Cultural Sciences, Lund University, Lund, 2013). – 4. EPSTEIN S, Inclusion: The politics of difference in medical research (The University of Chicago Press, Chicago & London,

2007). – 5. COOPER M & WALDBY C, Clinical Labor: Tissue Donors and Research Subjects in the Global Bioeconomy (Duke University Press, Durham & London, 2014). – 6. ARMSTRONG D, Sociology of Health & Illness, 36 (2014) 163. – 7. SEGAL JZ, Journal of Medical Humanities, 28 (2007) 81. – 8. CHARMAZ K, Good Days, Bad Days: The Self in Chronic Illness and Time (Rutgers University Press, New Brunswick, 1991). – 9. DE CERTEAU M, The Practice of Everyday Life (University of California Press, Berkeley, Los Angeles & London, 1984).

M. Idvall

Department of Arts and Cultural Sciences, Division of Ethnology, Lund University, Helgonavägen 3, 223 62 Lund, Sweden

e-mail: markus.idvall@kultur.lu.se

KONKORDANTAN PROSTOR BIOMEDICINSKE ZNANOSTI: KAKO SE OSOBE S PARKINSONOVOM BOLEŠĆU USKLAĐUJU SA KLINIČKIM ISTRAŽIVANJIMA

SAŽETAK

Parkinsonova bolest postaje sve je učestalija starenjem zapadnjačkih populacija. Postoji lijek Levodopa, ali je povezan s nuspojavama. U potrazi za alternativnom terapijom pacijenti djeluju na različite načine. Njihovo sudjelovanje u kliničkim istraživanjima nerijetko otvara mogućnost laičkog utjecaja na znanost. U ovome radu postavlja se pitanje kako se netko kao pacijent odnosi prema kliničkoj znanosti. Kako netko postupno prihvaća ono što, na temelju svoje degenerativne bolesti, shvaća kao napredak znanosti? Osobe oboljele od Parkinsonove bolesti su u tom smislu vremenski ograničena bića u svemu što čine ili kalkuliraju u vezi znanosti. Na temelju etnografskog istraživanja provedenog u okviru biomedicinskog znanstvenog projekta o transplantaciji stanica, u radu se preispituju dva različita pojma, konkordancija i sinkronizacija, s obzirom na njihov analitički potencijal za razumijevanje načina na koji pacijenti sudjeluju u kliničkim istraživanjima.