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, 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 paper we ask how one, as patient, relates to clinical science. How does one move along towards what one, on the basis of one’s degenerative illness, 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. In the paper, based on an ethnographic fieldwork within the frames of a biomedical research project on cell transplantations, two different concepts – concordance and synchronizing – will be explored in terms of their analytical potential for understanding how research patients participate in clinical trials.

Key words: 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 PD. Traditionally the disease has been a condition associated with ageing and the elderly. However, it is not unusual with individuals who get the disease already in their thirties and forties. PD is a brain disorder with severe and incapacitating somatic symptoms: tremor, rigid muscles, slowness, 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 disorder. The first symptoms an individual experiences 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 an 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 British doctor James Parkinson. This was in the beginning of the 19th century and the disease was called ‘shaking palsy’ at that time. The disease got 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 name. It is still not known what exactly causes the outbreak 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. Nevertheless, it has turned out that levodopa has great side-effects for individuals after some years of medication. These side-effects, involuntary movements of the body (dyskinesias) for example, can be as bad and as painful for the individual as the disorder itself.

Material and methods

Today there is an active biomedical research on PD in many parts of the world and within many fields of research. One of these research fields concerns transplanta-
tion of dopamine-producing neuron cells and stem cells into the brain of the invalid individual. This field has expanded a great deal over some decades ever since the first clinical trials were conducted in the second half of the 1980s. In present time there is an EU-funded program called TRANSEURO where a number of different neuro-scientific centers in Europe collaborate in order to realize new clinical trials with dopamine-producing cells. This program 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 program for some years. I have conducted observations in different settings as well as focus groups and individual interviews with clinical scientists, medical staff, patients, family members and public in order to learn more about what characterizes clinical research in a context where scientists and patients interact. 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 hereby establish a new conceptual space for how the two categories relate to each other.

Biomedical research is usually quite a hierarchical practice including only the researchers themselves as active agents, while patients, families and public often have been seen more as objects or instruments for conducting science in different ways. However, in the last few years there have been more and more studies within social sciences and humanities, which in different ways are challenging the dominance of the natural sciences by introducing a more participatory, inclusive as well as critical perspective on the issues. My own research is a part of 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 clinical science may be represented as. 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 ill individuals move along tactically in relation to how science, in parallel, moves into new stages and generates new expectations.

**Results and discussion**

Concordance, my first term here, has its conceptual background in a health care discourse around the year of 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 concordance was introduced as term 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.’ 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.’ Concordance, in Armstrong’s view, thus was meant to endorse ‘a form of open consultation that encouraged the patient[s] to express their true selves by verbalizing their inner life-worlds.’ 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’. 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.

Still, I want to 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 can say that there is a new space for cultural creativity in a relationship which historically has been rather fixed and conformist. Second, this 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). I think this patient-empowering aspect of concordance is what is 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 published in 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 chronically ill constitute their self and how they organize and cope with their lives.

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 rise in the relations between patients and clinical scientists even though the experiences and interests of the two categories may vary to a great extent. Through looking at concord rather than conflict I highlight how individuals time the tempo of their own embodied progress 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, etc. In my fieldwork I have encountered two discrete modes of synchronizing in relation to clinical trials in general and for patients.
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 got PD. She was in a state of shock and alienation in the beginning. 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 got in contact with individuals who were in her own age and who suffered from the disease. Now she decided to become more active in the patients’ organization. At that time she went to a lecture about a research project on cell transplantation which was to be launched. After the lecture she confronted the researcher who had lectured and asked whether 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 that were to be used might not become a method for everyone. Still, she wanted to test this possibility before she had come too far in the disease’s progression.

Since then, more than five years have passed. Annika has been part in the biomedical research project. First she was in a big observation group with different patients. Then she became part in a smaller group where she received 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 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 doing progress right now and she feels that she needs to catch up with this.

Navigating, the other form of synchronizing that I experienced as a challenge in many different respects. 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 analyses and comes to the final conclusions. Therefore the figure of the participating research patient can be experienced as a challenge in many different respects.

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 on the other – a new type of view where the ‘weaker’ part of the involved protagonists is given more space and possible impact than before. 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 analyses and comes to the final conclusions.
Acknowledgement

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


M. Idvall

Department of Arts and Cultural Sciences, Lund University, Helgonavägen 3, 221 00 Lund, Sweden
e-mail: markus.idvall@kultur.lu.se

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

SAŽETAK