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Coping with biomedical science

How individuals with Parkinson's disease synchronize themselves with clinical trials

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Coping with Biomedical Science:

How Individuals with Parkinson's Disease Synchronize Themselves with Clinical Trials

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Abstract:

Parkinson's disease has become more frequent as populations grow older in western countries. Since the 1960s a medication – levodopa – exists but it is connected with side-effects. Due to this there is a scientific search for new therapies in a global context. In many western countries Parkinson is explored within biomedical research fields such as genetics and cell transplantation.

In the last years I have followed a biomedical research project in Sweden focused on realizing clinical trials with Parkinson patients within the field of cell transplantation. In my work I have conducted interviews with patients, researchers and medical staff as well as observations in hospital environments and in contacts with patient's organizations.

My aim with this presentation is to explore what constitutes a clinical trial from the viewpoint of the patients. How does this biomedical research matter for trial-participating as well non-participating patients? How does one as patient follow and understand the clinical trials? How does one move along in relation to what one, on the basis of one's degenerative illness, perceives as the progress of science? Individuals with Parkinson are, in this sense, temporal beings in whatever they do or calculate in relation to science. Taking part in clinical trials is viewed as a way of synchronizing one's self with what one experiences as the tempo of practiced science. In my presentation I will explore different concepts for how a form of time sensitivity can be studied among patients.

Keywords: synchronizing, Parkinson's disease, clinical trials, participation, time, patient perspective