

Summary of the doctoral dissertation

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Thesis topic: Experiencing chronic illness with the example of people with multiple sclerosis

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The topic of the dissertation is the experience of chronic illness as exemplified by people with multiple sclerosis. The dissertation aims to analyse the individual experiences of people affected by multiple sclerosis and the impact of these experiences on their lives, daily functioning and interactions. It includes references to the key issues that make up the experience of chronic illness, and the views of researchers addressing this issue, such as Kathy Charmaz, Anselm Strauss, Barney Glasser, Juliet Corbin, Erving Goffman and others. The experience of chronic illness has been defined by the author as a process involving both the individual's individual experiences and the individual's inherent reactions to the symptoms experienced and the resulting limitations (physical, psychological and social). Thus, experiencing illness is a much broader concept than being ill. The multidimensional and diverse dimensions of chronic illnesses have given rise to a specific field of research in the sociology of medicine on the *illness experience*.

The paper contains two theoretical chapters, a methodological chapter, a presentation of the results of the analysis of the empirical material carried out, and a conclusion, which includes conclusions from the research and recommendations that can be used to develop measures to support people with multiple sclerosis (at different stages of the disease).

The dissertation includes references to personal and social identity in terms of interpretative sociology and, in particular, symbolic interactionism. It was symbolic interactionism that provided the theoretical and methodological framework for the entire consideration of the experience of chronic illness, as well as the entire research project described in the dissertation. In interactionist terms, identity is a kind of consensus of meanings that are attributed to a social actor and at the same time a participant in a given situation by the actor himself and other participants in the interaction. The investigations in the first theoretical chapter refer to the characteristics of identity, how this identity changes as a result of the experience of illness. This section also addresses the identity formation process of the sick person, referring to the trajectory of chronic illness, taking into account the dynamic nature of the formation and (re)construction of the sick person's identity as a result of the illness experienced and the limitations associated with it. The first chapter of the dissertation includes both the definitions of experiencing illness presented on the grounds of interpretative sociology, as well as how it was defined by the author of the dissertation. As part of the consideration, the author addressed the issue of life interruption under the influence of chronic illness. The last subsection in this part of the discussion is devoted to the issue of social roles (in general), the

role of the sick person and how these social roles are shaped as a result of chronic illness, which restricts and often completely prevents patients from fulfilling certain social roles. This section also includes the social expectations formulated towards the chronically ill.

The second theoretical section presents definitions of chronic illness, references to disability as an individual's activity limitations. Included in this section are references to the social effects resulting from disability caused by chronic illness (i.e. the resulting limitations on the individual's life and relationship with Others). In the second theoretical chapter, the author presented how pain, changes in appearance and limitations in bodily function affect the sick individual's perception of themselves and their interactions with their environment. Furthermore, the second chapter presented the psychological (cognitive and emotional) changes that people affected by a chronic condition may experience, as well as the strategies and defence mechanisms used by patients. This section also shows the role of the family in supporting and caring for the person with a chronic illness. This section also covered the medical aspects of multiple sclerosis. These only complemented the social theories presented in the two theoretical chapters. In addition, this part of the thesis discusses the most important issues related to the disease that emerged from the statements of the interviewees and the analysis of the interviews. A characterisation of multiple sclerosis was presented, which provided a kind of interpretive context for the empirical section. The author did not include a presentation of all medical issues related to multiple sclerosis, only those she considered crucial to better understand the reflections of those who took part in the study.

The third chapter of the dissertation was devoted to methodological issues. It describes the entire research process, from the conceptualisation of the research, to the conduct of the research, to the subsequent analysis of the results obtained from the interviews and the content analysis of the online support group for people with multiple sclerosis. The subjects of the study were the respondents' stories about their daily life with a chronic disease. The colloquial picture of the social world presented by the respondents was important to the researcher during the analysis of the statements of the patients. The aim of the research was to attempt to reconstruct the complex process of the respondents' experience of chronic illness and the meanings the patients attributed to their own illness. The research contributed to a better understanding of the complexity of the process of experiencing the illness, the reconstruction of the respondents' identity (under the influence of the illness) and the discovery of the ways in which the respondents interpreted their experiences and how they translated them into the actions they took. In the course of the study, 35 free, in-depth interviews were conducted with people who had the remission-relapsing form of multiple sclerosis and were qualified for the state multiple sclerosis treatment programme. Each time, the location of the meeting was determined by the respondents, so the interviews took place across the country. The qualitative research that was carried out during the research project took into account the individual perspective and experiences of the respondents. Their use enabled an analysis (at a later stage) of the personal experiences of patients with a diagnosis of multiple sclerosis, taking into account their subjective perspectives, which were expressed in each of the interviews conducted. Entries on an online multiple sclerosis support group were also used for the study. All stories and postings quoted in the study were anonymised to make it *as impossible as possible* to identify their authors.

During the analysis of the material obtained (both through the interviews and the online support group), a coding procedure based mainly on the studies by Kathy Charmaz was applied. Already at the stage of analysing the individual interviews, an *open coding* method was used, in which conceptual labels were given to individual events extracted from the interviewees' statements. Also in the subsequent stages of analysis, open coding was used by comparing the individual statements of the interviewees with each other. Codes were then constructed that matched a larger batch of extracted material, which was the moment to move to a more advanced stage of coding, which is called focused coding. The analysis of the content published on the online group proceeded in the same way.

The fourth chapter contains an analysis of the material obtained during the research conducted. In the course of the analytical process, the phases that make up the process of experiencing chronic illness by those who took part in the study were identified. In addition, an attempt was made to reconstruct and present the meanings that the respondents gave to their illness, which they conveyed in their stories. On the basis of the analysis of the empirical material, the first phase, during which the respondents experienced the first harbingers of the illness, was distinguished. Due to their ambiguous nature, often lower intensity and/or frequency, they were not defined as a symptom of a serious illness (by both patients and doctors). The second phase consisted of symptoms that significantly disrupted the lives of the subjects, so that the patients (often under pressure from their environment) decided to contact a doctor and undertake a detailed diagnosis. The third phase identified was the period of hospitalisation and the moment when the subjects received a diagnosis of multiple sclerosis. The next phase was the stage of initial familiarisation with the diagnosis, which took place immediately after the subjects returned home and began to develop action strategies. This was the initial stage of the adaptation process to a new reality - living with a chronic disease. The last phase that emerged in the analysis was living with a chronic illness. It was divided into two categories. The first was 'living with the illness' - within this, patients treated the illness as something external. It often involved an attitude of rejection of the role of the patient and a lack of acceptance of their own condition. The second category is "living with the illness". It includes attitudes in which the illness comes to the fore in the lives of the respondents. The empirical chapter (within each of the 5 phases) presents ways of coping with the illness, both on a physical and emotional level. Issues related to the patient's identity, such as the redefinition of oneself in the context of the illness, the acceptance of the illness and its impact on relationships with other people, are also included.

The final part of the discussion consists of the conclusions drawn from all the considerations, and in particular from the research carried out. The analysis of the material obtained made it possible to identify the needs and expectations of people with multiple sclerosis with regard to the support offered to them. Practical implications were suggested for interdisciplinary action for people coping with the chronic disease. Indeed, the need for additional support systems that take into account the needs of people with a chronic disease, including multiple sclerosis, was identified.

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