

Disability in the Course of a Chronic Disease: The Example of People Living with Multiple Sclerosis in Poland

Authors : Milena Trojanowska

Abstract : Disability is a phenomenon for which meanings and definitions have evolved over the decades. This became the trigger to start a project to answer the question of what disability constitutes in the course of an incurable chronic disease. The chosen research group are people living with multiple sclerosis. The contextual phase of the research was participant observation at the Polish Multiple Sclerosis Society, the largest NGO in Poland supporting people living with MS and their relatives. The research techniques used in the project are (in order of implementation): group interviews with people living with MS and their relatives, narrative interviews, asynchronous technique, participant observation during events organised for people living with MS and their relatives. The researcher is currently conducting follow-up interviews, as inaccuracies in the respondents' narratives were identified during the data analysis. Interviews and supplementary research techniques were used over the four years of the research, and the researcher also benefited from experience gained from 12 years of working with NGOs (diaries, notes). The research was carried out in Poland with the participation of people living in this country only. The research has been based on grounded theory methodology in a constructivist perspective developed by Kathy Charmaz. The goal was to follow the idea that research must be reliable, original, and useful. The aim was to construct an interpretive theory that assumes temporality and the processuality of social life. The Atlas.ti software was used to collect research material and analyse it. It is a program from the CAQDAS (Computer-Assisted Qualitative Data Analysis Software) group. Several key factors influencing the construction of a disability identity by people living with multiple sclerosis was identified: - course of interaction with significant relatives, - the expectation of identification with disability (expressed by close relatives), - economic profitability (pension, allowances), - institutional advantages (e.g. parking card), - independence and autonomy (not equated with physical condition, but access to adapted infrastructure and resources to support daily functioning), - the way a person with MS construes the meaning of disability, - physical and mental state, - medical diagnosis of illness. In addition, it has been shown that making an assumption about the experience of disability in the course of MS is a form of cognitive reductionism leading to further phenomenon such as: the expectation of the person with MS to construct a social identity as a person with a disability (e.g. giving up work), the occurrence of institutional inequalities. It can also be a determinant of the choice of a life strategy that limits social and individual functioning, even if this necessity is not influenced by the person's physical or psychological condition. The results of the research are important for the development of knowledge about the phenomenon of disability. It indicates the contextuality and complexity of the disability phenomenon, which in the light of the research is a set of different phenomenon of heterogeneous nature and multifaceted causality. This knowledge can also be useful for institutions and organisations in the non-governmental sector supporting people with disabilities and people living with multiple sclerosis.

Keywords : disability, multiple sclerosis, grounded theory, poland

Conference Title : ICDD 2023 : International Conference on Disability and Diversity

Conference Location : Paris, France

Conference Dates : November 27-28, 2023