

# Jordan University of Science and Technology

## Perspective and experiences of Jordanian people with multiple sclerosis?A qualitative study [abstract]. ," Multiple Sclerosis Journal, vol. S

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**Abstract:** Background/Objective: The prevalence rate of MS is estimated to be around 39 cases per 100,000 in Jordan. Individuals with Multiple Sclerosis (MS) have a reduced health-related quality of life and increased psychological and physical morbidity. Studies suggest that qualitative research can help more in the exploration of hidden aspects of human concepts, such as culture, perception, perspectives, attitudes, and ideas about chronic diseases. However, There has been little attempt to conduct qualitative studies concerning the experience of living with MS specifically in the developing counties such as Jordan. Exploring this information provide a background to understand the importance of an individual?s social identity on their well-being and hope. Therefore, this study was conducted to describe the experiences of Jordanian people with multiple sclerosis. Methods: Four focus groups were conducted with people with MS (n=16). Conversations were digitally recorded and transcribed. Transcripts were analyzed using thematic analysis and validated via researcher triangulation and peer checking. Results: Two main themes were emerged from the data that reflect patients? experiences on living with MS; the first theme related to their experiences with the health care system, while second theme related to their experiences with the disease itself. Most of the participants had difficult time to reach accurate diagnosis. Also, all the participants reported lack/bad communication from neurologists especially at the time of the diagnosis which left them in dilemma, relying only on medication and not knowing what else to do to improve their quality of life such as rehabilitation and physical activity. Fatigue, fears and uncertainty about the symptoms and future are the most common disease related issues that people with MS experienced and have been associated with reduced quality of life, depression, and Stigma. Lack of awareness about MS disease among general people or even among hea