EPILEPSY: DOES STIGMA STILL EXIST?

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Introduction: Patients with epilepsy (PWE) still perceive epilepsy-related prejudice, myths, and stigmas.

Objective: To study how PWE perceive stigma and its correlations with clinical aspects.

Casuistic and procedures: Sixty-nine consecutive, male and female (44) PWE with a mean age of 42.1 (±14.4) years followed at PUC-Campinas were studied. They were submitted to clinical and neurological examinations; digital electroencephalogram (EEG); brain magnetic resonance imaging (MRI); Quality of Life in Epilepsy Inventory (QOLIE-31); and Stigma Scale of Epilepsy (SSE). The study investigated whether SSE related to clinical aspects and QOLIE-31 scores at a significance level of p0.05.

Results: The mean SSE and QOLIE-31 scores were 46.2 (\pm 17) and 62.1 (\pm 8.8), respectively. Mean age at first epileptic seizure (ES) was 19.0 (\pm 15) years, and mean disease duration was 23.0 (\pm 14.1) years. Eighteen patients were seizure-free for more than one year. Eleven (15.9%) patients had idiopathic generalized epilepsy, 37 (53.2%) had symptomatic focal epilepsy, and 21 (30.4%) had probably symptomatic focal epilepsy. SSE correlated negatively with the overall QOLIE-31 score (Spearman's correlation,-0.390; p=0.005) and with the QOLIE-31 dimensions "seizures worry" (-0.328; p=0.02); "cognitive" (-0.405; p=0.004), and "social function" (-0.536; p=0.004). SSE scores did not correlate with clinical aspects.

Discussion and conclusion: The stigma perceived by PWE was high and not associated with epilepsy characteristics. However, stigma correlated negatively with quality of life. These findings suggest that stigma may worsen PWE's quality of life.