

Stigma and social isolation in patients with non-epileptic seizures

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ABSTRACT

OBJECTIVE: Despite the prevalence of stigma associated with non-epileptic seizures (NES), few studies have examined the impact of stigma on patients with NES. We quantitatively characterized the prevalence, severity, and sociodemographic associations of three types of stigma reported by patients with NES.

METHODS: Participants were sampled among patients referred to the University of Colorado NES Clinic for treatment. Patients with NES completed questionnaires to measure different types of stigma. The Epilepsy Stigma Scale (ESS) measured both perceived and internalized stigma, the Internalized Stigma of Mental Illness (ISMI-9) measured internalized stigma, and the Quality of Life in Neurological Disorders Stigma Short Form (Stigma Short Form) measured both internalized and experienced stigma. One-way ANOVA and pair-wise differences in the mean were used to analyze the association between stigma and sociodemographic characteristics.

RESULTS: Of 126 patients who participated in the study, the median age was 33.7 years old, 79.4% identified as female and 16.7% identified as male. In our sample, 73.8% reported feeling internalized stigma on the ISMI-9, with 32.5% reporting severe levels of internalized stigma. Higher levels of stigma were associated with reported suicidal thoughts ($p=0.03$), single relationship status ($p=0.05$), or unemployment ($p=0.02$). Patients reported a mean total score of 4.9 (SD 1.4) on the ESS, indicating

perceived stigma. Higher levels of perceived stigma were associated with single relationship status ($p=0.05$) and not driving ($p=0.05$). On the Stigma Short Form, patients rated a mean T-score of 61.3, which was 1SD above a clinical reference population. Higher levels of stigma were associated with not driving ($p=0.02$).

CONCLUSION: Internalized stigma is not only prevalent and severe, but it is also associated with suicidal thoughts. Socially isolating factors were associated with experienced, perceived, and internalized stigma. Future studies should further examine the impact of internalized stigma on quality of life, the relationship between stigma and social isolation, and targets for stigma mitigation.