



## Factors associated with perceived stigma of epilepsy in Croatia: A study using the revised Epilepsy Stigma Scale



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### ABSTRACT

**Purpose:** It is believed that a large number of factors influence feelings of stigma, but their relative contribution is not yet entirely clear. Most studies to date were conducted using the Epilepsy Stigma Scale (ESS); only one used a revised version of the ESS (rESS). The following study aims to determine factors contributing to epilepsy stigma in outpatients with chronic epilepsy in Croatia, and to analyze some psychometric properties of the Croatian translation of the rESS.

**Methods:** Alongside standard testing for validity of the scale, a simulation model of the original ESS (smESS) was created. This model, which does not include a grading Likert 0–3 scale, was compared with the rESS.

**Results:** In total, 159 out of 298 subjects (53%) reported feeling stigmatised, with 136 (45%) mild to moderately and 23 (8%) highly. Internal consistency of the Croatian translation of the rESS was 0.887.

Feelings of stigma were significantly associated with age  $\leq 50$  years, younger age of epilepsy onset, more than 50 seizures to date, generalized tonic–clonic seizures, and a shorter seizure-free period. Multiple stepwise regression showed number of seizures to date as a significant variable (Beta = 0.246).

By adapting data into the smESS significant associations with younger age and age of epilepsy onset were lost. Internal consistency of the smESS was 0.849.

**Conclusions:** The Croatian translation of the rESS has been proved to be a suitable instrument for diagnosing epilepsy stigma. The results of our model point to the possibility that the rESS might be more sensitive than the original ESS.

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## 1. Introduction

Epilepsy is a condition highly associated with feelings of stigma.<sup>1,2</sup> This is universally true among countries with different cultural backgrounds.<sup>3–6</sup> In Europe, the frequency of epilepsy patients experiencing stigma is reported as between 31% and 69%.<sup>3,4,7–11</sup> It is believed that a large number of factors influence feelings of stigma, ranging from social circumstances and seizure control to psychological traits of individuals with epilepsy. Some of the important factors seem to be number of seizures and seizure-free period, compliance with medication, age and age of epilepsy onset, employment status, level of family functioning, degree of

self-esteem, and experience of anxiety and depression.<sup>3,6,7,10–14</sup> However, the relative contribution of these factors to stigma seems to vary across different European countries.<sup>6,15</sup>

Many studies addressing the contribution of different factors to stigma used the Epilepsy Stigma Scale (ESS), first described by Jacoby in 1992,<sup>16</sup> and later revised in order to detect more subtle differences in levels of felt stigma. So far, this revised stigma scale (rESS) has been used in only one study of subjects with recently diagnosed epilepsy,<sup>11</sup> as a subgroup of patients with epilepsy included in the SANAD trial.<sup>17,18</sup> In all other studies,<sup>3,16,19–22</sup> including the most recent one,<sup>7,8</sup> the original version of the scale was used.

Research on epilepsy stigma in Croatia has not yet been performed. Our initial hypothesis was that the prevalence of stigmatisation due to epilepsy would be similar to other European countries, but also that by utilizing the rESS, risk factors for stigma could be identified more precisely. Therefore, the aims of this study were to (1) determine factors contributing to feelings of stigma in

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outpatients with chronic epilepsy in Croatia and (2) analyze some psychometric properties of the Croatian translation of the rESS. Alongside standard testing for validity of the scale, a simulation model of the original Epilepsy Stigma Scale (smESS) was created. This model, which does not include a graded Likert 0–3 scale for each of the questions, was compared with the rESS. With this approach, we wanted to test the potential advantages of the rESS in epilepsy stigma research.

## 2. Methods

### 2.1. Subjects

Subjects were patients with epilepsy who attended regular visits as outpatients at one of the three participating hospital-based epilepsy services for adults in Croatia. Exclusion criteria were: inability to fill in the provided questionnaire without help, not taking AEDs and epilepsy that was diagnosed during the previous 6 months. The data were collected in each of the affiliations over 6 weeks, from the beginning of April until the end of May 2012.

### 3. Questionnaire

Subjects were asked to complete a questionnaire containing 9 questions concerning demographic data and clinical features of their epilepsy, and the revised version of the Epilepsy Stigma Scale (rESS), translated into Croatian. An official interpreter, together with the author of this study, has endorsed the Croatian translation. When completing the rESS, individuals are asked to respond on a scale of 0–3 (0 = not at all, 1 = yes, maybe, 2 = yes, probably, 3 = yes, definitely) whether, because of their epilepsy, they feel that other people are (1) uncomfortable with them, (2) treat them as inferior and (3) prefer to avoid them. In this way, a total score of 0–9 is obtained, where 0 represents no stigma, a score of 1–6 represents mild to moderate stigma, and a score of 7–9 represents high stigma.<sup>11</sup> Demographic data included age, sex, marital status, level of education and employment status. Clinical features included age of epilepsy onset, approximate number of all seizures, approximate number of 'major' seizures to date, and time period since the last seizure. In Croatian colloquial language, a generalized tonic-clonic seizure (GTCS) is better known as a 'major' seizure, so in the questionnaire we used this term instead of GTCS because we estimated that a proportion of subjects would not understand the clinical term. However, we report results pertaining to this question using the term GTCS. Number of seizures was a multiple-choice question with the following possible answers: *Less than 5*, *5–10*, *10–50*, *50–100* and *More than 100*, while the question about major seizures had the additional choice – *None*. Age of epilepsy onset and time period since the last seizure was free-response questions and these data were used to calculate duration of epilepsy (in years) and seizure-free time period (in days). When analysing education levels, subjects were divided into three categories: (1) elementary school, (2) secondary school and (3) college/school of higher education/university. When analysing employment status, subjects were divided into two categories: (1) unemployed/retired/disabled and (2) employed/in education.

### 4. Simulation model of the ESS (smESS)

In the original version of the ESS, individuals are asked to respond to the same three items, but instead of using a Likert scale 0–3, possible answers are dichotomous (either 'yes' or 'no'). In this way, the total score of the ESS is 0–3. We tried to make a simulation model of this version of the ESS based on the assumption that a

subject who reported not feeling stigmatised when completing the rESS would choose the same answer when completing the ESS. Based on this assumption, using the answers obtained from the rESS, our smESS was calculated in the following way: if the answer was 0 (not at all), it remained 0, and if it was either 1, 2 or 3 (yes maybe, yes probably or yes definitely), it was scored as 1. In this way, the total score of the smESS was 0–3.

## 5. Statistics

For statistical analysis, IBM SPSS Statistics, Version 20.0 was used. Evaluation of the internal consistency of the scale was estimated by Cronbach's  $\alpha$  test. Groups of subjects having no stigma, mild-to-moderate stigma and severe stigma were compared to find differences in clinical and demographic characteristics using analysis of variance and the  $\chi^2$  test, as appropriate. The analysis was performed separately using the smESS, and the results were compared with the ones using the rESS. For the multiple regression analysis, a stepwise model was used to determine the most significant variables among independent variables that were expected to have an influence on the total stigma scale score: age, age of epilepsy onset, duration of epilepsy and seizure-free period as continuous variables; sex, marital status and employment status as dichotomous variables and level of education, number of seizures and number of 'major' seizures as ordinal variables. Values of  $p < 0.05$  were considered significant.

## 6. Results

Questionnaires were obtained from 310 subjects. None of the subjects who were asked to fill in the questionnaire refused to do so, but 12 (4%) failed to respond to at least one of the items on the stigma scale, so analysis was done on 298 subjects. Some of the respondents also failed to adequately answer one or more of the remaining questions, with the question about time since last seizure producing the most frequently missing or inadequate answers (32/298). These data, along with demographic and clinical characteristics, are shown in Table 1.

Internal consistency of the rESS was 0.887.

In total, 159 subjects (53%) reported feeling stigmatised, with 136 (45%) mild to moderately and 23 (8%) highly. Frequency of subjects feeling stigmatised did not differ significantly between the three outpatient centres (Centre No. 1: 51% of 76 subjects, Centre No. 2: 53% of 91 subjects, Centre No. 3: 54% of 131 subjects).

Feelings of stigma were associated with age  $\leq 50$  years ( $\chi^2 = 6.435$ ,  $df = 2$ ,  $p = 0.040$ ), younger age of epilepsy onset ( $F(2,289) = 4.635$ ,  $p = 0.010$ ), more than 50 seizures to date ( $\chi^2 = 11.536$ ,  $df = 2$ ,  $p = 0.003$ ), experiencing GTCS seizures ( $\chi^2 = 7.085$ ,  $df = 2$ ,  $p = 0.029$ ) and a shorter seizure-free period ( $F(2,264) = 3.420$ ,  $p = 0.034$ ) (Table 2). No statistically significant association was found between stigma and sex, marital status, level of education, employment status or duration of epilepsy.

When multiple stepwise regression was performed, a significant model emerged ( $F(1,237) = 15.329$ ,  $p < 0.001$ , adjusted  $R^2 = 0.057$ ), with only one significant variable – number of seizures to date (Beta = 0.246), i.e. subjects who experienced more seizures had higher levels of stigma.

By adapting the obtained data into the smESS as described in Methods, associations of stigma score with more than 50 seizures to date ( $\chi^2 = 8.784$ ,  $df = 3$ ,  $p = 0.032$ ), GTCS ( $\chi^2 = 7.896$ ,  $df = 3$ ,  $p = 0.048$ ) and a shorter seizure-free period ( $F(3,263) = 3.367$ ,  $p = 0.019$ ) remained significant, while significant associations with age  $\leq 50$  years ( $\chi^2 = 5.649$ ,  $df = 3$ ,  $p = 0.130$ ) and younger age of epilepsy onset ( $F(3,288) = 1.538$ ,  $p = 0.205$ ) were lost (Table 3). Internal consistency of the smESS was slightly lower than for the rESS, at 0.849.

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