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Impact of stigma on the quality of life of patients with refractory epilepsy

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ABSTRACT

Purpose: To assess the impact of perceived stigma on the quality of life of Bulgarian patients with refractory epilepsy.
Methods: We studied 70 adult patients with refractory epilepsy, without cognitive impairment, progressive somatic, neurological disease or recent seizures, and 70 patients with pharmacosensitive epilepsy. All participants completed a 3-item stigma scale, the patients with refractory epilepsy also completed a Health Related Quality of Life measure (the QOLIE-89).
Results: The patients with refractory epilepsy had a mean disease duration 25.1 ± 1.3 years. 40.0% of patients (±5.9) had symptomatic epilepsy. Seventeen patients (24.2% ± 5.1) had partial seizures, 16 (22.8% ± 5.0) had generalized seizures and 37 (52.9 ± 6.0) had a mixture of partial and generalized seizures. Most participants had several seizures per week (45.7%) or month (30.0%) despite the fact that 90% were taking combination antiepileptic drug treatment. We found perceived stigma in 43.6% of patients with refractory epilepsy, and 28.7% self-reported severe stigmatization. Only 4 (5.7%) patients with pharmacosensitive epilepsy reported stigmatization which was mild or moderate in all cases. Perceived stigma had a negative impact on the overall score of the QOLIE-89 (*T*-score 47.8), as well as on all subscales of QOLIE-89, with the exception of "change in health" and "sexual relations". Patients with refractory epilepsy reporting stigmatization most commonly had very low and low scores on the subscales "health perceptions" (82.9%), "emotional well-being" (71.5%), "memory" (63.4%) and "health discouragement" (62.5%). There was a negative correlation of all QOLIE-89 subscales with perceived stigma severity.
Conclusion: All aspects of the quality of life of Bulgarian patients with refractory epilepsy correlate negatively with the severity of perceived stigma.
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1. Introduction

Stigma was defined by Link and Phelan (2001) as a social process that is observed when there are elements of labeling, stereotyping, and discrimination because of characteristics previously specified as different and unacceptable, which result in social status loss.[1] Health-related stigma is based on a special characteristic of a health problem or a state.[2] Stigma worries the patient more than the disease itself, makes the patient feel guilty, and is associated with depression.[3] In patients with epilepsy, stigma is a result of the unpredictability of seizures and social exclusion due to a negative attitude of society, including difficulties in education, having a family, and finding a job, even when it is not contraindicated.[4] Because of stigmatization, patients hide the disease from relatives, partners, and employers.[5] The frequency of stigmatization varies from 31% to 54%, and in 9% to 29.3% of patients, it is severe.[3] In persons with epilepsy, perceived stigma (i.e., feelings of devaluation, shame, secret, or withdrawal caused by applying negative stereotypes to the subject) has been investigated most frequently by means of appropriate questionnaires.

Epilepsy has a great influence on the three levels of quality of life (physical, mental and social health), an influence that is exercised directly by affecting physical and mental health and indirectly by introducing limitations and decreasing the opportunities for taking part in quality of life improving activities. The results from a number of studies have proven that the stigmatization in this group of patients is one of the factors contributing to quality of life decrease.[6–9]

No study of stigma and its impact on the quality of life of patients with epilepsy has been performed in Bulgaria.

1.1. Purpose of the study

Assessment of the impact of perceived stigma on the quality of life of Bulgarian patients with refractory epilepsy.

1.2. Patients and methods

The study was performed with the participation of 176 consecutive patients with refractory epilepsy and 70 consecutive

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patients with pharmacosensitive epilepsy who attended the Clinic of Neurology at the University Hospital in Plovdiv, Bulgaria for a regular examination, for cases of unsatisfactory seizure control or for adverse events from treatment.

All study procedures were performed after the approval of the Local Ethics Commission at the University of Medicine, Plovdiv. Every patient was introduced to the study design and signed an informed consent form before participation in study procedures.

We used the following inclusion criteria: a signed informed consent form; age between 18 and 65 years; a diagnosis of refractory epilepsy; lack of cognitive impairment based on Evaluation Rapide des Fonctions Cognitives (ERFC; Gil and Toullat, 1986), with a score <47 in patients up to 60 years of age and primary education or <46 in patients between 60 and 65 years of age and less than a primary education or illiterate; lack of progressive somatic or neurological disease; lack of simple or complex partial seizures in the last 4 h; and lack of generalized tonic-clonic seizures in the last 24 h. We accepted epilepsy as refractory in cases in which adequate seizure control with at least two potentially effective antiepileptic drugs prescribed as monotherapy or combination at maximal tolerated doses had not been achieved. After excluding 39 patients with pseudo-refractory epilepsy (in cases with diagnostic, therapeutic errors or poor compliance), 2 patients older than 65 years, 2 patients with progressive neurological disease, 5 patients with a simple or complex partial seizures in the last 4 h or a generalized tonic-clonic seizure in the last 24 h, and 58 patients with cognitive impairment, 70 patients with refractory epilepsy and 70 patients with pharmacosensitive epilepsy remained in the study.

The data were collected through an interview and examination of the patients' medical documentation.

Twenty one (30.0% ± 5.5) of the participants with refractory epilepsy were men; the remaining 49 (70.0% ± 5.5) were women. The mean patient age was 41.7 ± 1.1 years. Most participants (76.6%) were between 30 and 60 years of age. The mean disease duration was 25.1 ± 1.3 years. Of the patients with pharmacosensitive epilepsy, 34 (48.6%) were men, and 36 (51.4%) were women; their mean age was 36.7 ± 1.5 years. There was no significant difference between both groups regarding their gender ($P > 0.05$, $\chi^2 = 2.4$) and age ($P > 0.05$, $u = 0.6$).

Patients with refractory epilepsy and pharmacosensitive epilepsy completed the stigma scale (MD Hyman, 1971); a Health Related quality of life measure (the QOLIE-89) was completed only by patients with refractory epilepsy. The stigma scale consists of three questions pertaining to patients' opinions about the attitudes of people. The possible answers are "yes" and "no." The severity of perceived stigma depends on the number of positive answers. If there is one affirmative response, we accepted the patient as stigmatized. The scale scores are as follows: 0 = "none", 1 = "mild", 2 = "moderate", and 3 = "severe". The scale has been applied by Jacoby et al.[1] in patients with epilepsy, and is known to have satisfactory convergent validity and internal consistency.[2]

QOLIE-89 is the most understandable and most widely used instrument for quality of life assessment in patients with epilepsy. It is the scale that includes the greatest number of epilepsy-associated factors. QOLIE-89 has been approved for research, and it is completed in 45 min. This scale enables the discrimination of minimally expressed but significant life quality changes in these patients. QOLIE-89 contains 89 items that are distributed in 17 subscales, characterizing 4 basic factors directed toward epilepsy, physical, mental, and social health. Except for the standard scores, the so-called "T-scores" for each of the 17 scale final scores and the overall score are calculated. The *T*-scores represent linear transformations of the scores that produce a mean of 50 and a standard deviation of 10 for the cohort of 304 adults with epilepsy. Higher *T*-scores reflect a more favorable quality of life.

In the course of the study, we made a validation of the Bulgarian translation of QOLIE-89 and proved its reliability, internal consistency (the mean of Crohnbach's α was 0.9 ± 0.0; the coefficient of Spearman–Brown was 0.9; the mean inter-item correlation was 0.3; we calculated a high coefficient of correlation between the subscales scores and the overall score in two completions of the questionnaire [r_{xy} = 0.8–1.0]) and validity (strong correlations between the overall scores of QOLIE-89 and QOLIE-31 [r_{xy} = 0.9] and between their corresponding subscales were found [r_{xy} = 0.9–1.00]).[10]

The collected primary information was checked, encoded, and entered into a computer database for statistical analysis. Data were processed using STATA Version 10 (Stata Corp., College Station, TX, U.S.A.) and SPSS (Statistical Package for the Social Sciences), version 14.0 (SPSS Inc., Chicago, IL, USA). The results for quantitative variables were expressed as the mean ± SE (standard error), and the results for qualitative variables were expressed as percentages ± SE. Age, gender, clinical findings, stigmatization of patients with refractory and pharmacosensitive epilepsy, as well as the assessments of the subscales and the overall score of QOLIE-89 made by stigmatized and non-stigmatized patients, were compared by means of χ^2-test and *Z*-test. Spearman coefficient (r_s) was used to analyze the correlation between stigma and the assessments of the subscales, as well as the overall score of QOLIE-89. Pairwise comparisons between the scores of the non-stigmatized patients and those of the mildly to moderately stigmatized patients were performed according to the Hochberg procedure to maintain an overall 5% type I error.

2. Results

2.1. Clinical findings of study participants

The clinical findings of the study participants are shown in Table 1.

2.2. Perceived stigma of study participants

According to the results from the stigma scale, 26 (37.1%) of the patients with refractory epilepsy reported stigmatization. Seven (10%) of all participants with refractory epilepsy were mildly stigmatized, 3 (4.3%) were moderately stigmatized, and 16 (22.9%) were severely stigmatized. Only 4 (5.7%) patients with pharmacosensitive epilepsy were mildly or moderately stigmatized. There were no participants with both pharmacosensitive epilepsy and severe stigmatization. With respect to the perceived stigma, a significant difference between patients with refractory and pharmacosensitive epilepsy was demonstrated ($P < 0.001$, $\chi^2 = 23.0$).

2.3. QOLIE-89 results

The mean overall score of QOLIE-89 given by the patients with refractory epilepsy was 64.3 ± 17.1. In our data analysis, the *T*-scores were used for a more explicit comparison with the mean scores of the epileptic population. The obtained scores were accepted as very low (≤35), low (36–45), medium (46–55) and high (>55). As a *T*-score, the mean overall score of QOLIE-89 was lower than the mean of the epileptic population ($x = 47.8$). Low mean scores were obtained for the subscales "Health perceptions" ($x = 39.4$), "Sexual relations" ($x = 42.5$) and "Overall quality of life" ($x = 42.8$). The mean scores of all other subscales were close to the mean of the epileptic population.

The subscales of QOLIE-89 were distributed in the following 5 groups: subscales associated with physical health, subscales associated with mental health, subscales associated with social health, subscales associated with epilepsy, and subscales associated

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