



Enacted stigma among patients with epilepsy and intellectual impairment

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ABSTRACT

Background: The limited research on stigma and its determinants in patients with epilepsy and intellectual impairment motivated our study in this area.

Purpose: We assessed enacted stigma and its determining factors in Bulgarian patients with refractory epilepsy and intellectual impairment.

Methods: We conducted a study of 64 patients with refractory epilepsy and intellectual impairment based on a questionnaire designed for people with intellectual impairment (stigma scale) and a purposeful interview on clinical factors and real experiences of discrimination, insults and/or threats, and attacks.

Results: A real experience of discrimination was reported by 51 (91.07%) of the interviewed participants, 34 (60.71%) of whom had been insulted and/or threatened and attacked because of their health problems. The experience of insults and/or threats and attacks was more frequent in cases with moderate intellectual impairment ($\chi^2 = 5.17, P < 0.05$). Discrimination was reported more rarely by older patients ($F = 3.23, P < 0.05$). The participants who gave a greater number of positive answers about experienced discrimination or insults and/or threats and attacks reported a more pronounced perceived stigma ($F = 19.30, P < 0.001$ and $F = 12.91, P < 0.001$, respectively). Perceived stigma and the experience of insults and/or threats and attacks proved to be predictors of discrimination on multivariate regression analysis ($F = 40.54, P < 0.001$).

Conclusions: We have affirmed very frequent enacted stigmatization in Bulgarian patients with refractory epilepsy and intellectual impairment and its correlation with the degree of intellectual impairment, age, and perceived stigma.

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1. Introduction

A 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 previously specified characteristics that are different and unacceptable, which result in social status loss [1]. The following categories of stigma are recognized: enacted stigma (a real experience of discrimination and/or abuse) and self-stigma (or internalized stigma, a feeling of devaluation, shame, secrecy, or withdrawal caused by applying negative stereotypes to the subject [2] or fear of discrimination [3]). Perceived stigma is generally used to refer to the extent that the patient believes that he or she will be stigmatized by the general public. The attitude of the community or specific groups towards patients is also important for the complete characterization of stigma.

Epilepsy is not only a medical diagnosis but also a type of a social label that is a result of the unpredictability of seizures. Social exclusion often occurs due to the negative attitude of society, including difficulties in education, having a family, and finding a job, even when these activities are not contraindicated [4]. Thus, the phenomenon of stigmatization is fairly frequent in people with epilepsy [5].

People with intellectual impairment are among the most stigmatized groups in society. They encounter prejudice, social exclusion, and major barriers that restrict their human rights [6]. Qualitative research has shown that people with cognitive problems are aware of being stigmatized and attempt to hide their impairment as a way of avoiding the social consequences of stigma [7,8]. The awareness of stigma appears to be related to the extent to which individuals accept and internalize the label of intellectual impairment [9]. Enacted stigma has also been described in people with intellectual impairment. The experience of stigma may involve overt acts of abuse or discrimination or may be more subtle, such as being denied the right to make choices or having over-protective families [10–12]. There is evidence that a stigma may have a negative impact on psychological well-being [9].

Therefore, patients with both cognitive problems and epilepsy have even more significant prerequisites for stigmatization. The stigma of

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people with epilepsy and intellectual impairment, however, is often neglected by health professionals. The lack of precise data from previous related research motivated our study of enacted stigma and a wide range of hypothetical determinants (demographic, mental, clinical) in patients with epilepsy and intellectual impairment. The confirmation of stigma determinants is needed and very important for timely measures to prevent stigma at the individual and public health levels.

1.1. Purpose of the study

We assessed enacted stigma and its determining factors in Bulgarian patients with both intellectual impairment and refractory epilepsy (RE).

2. Method

All study procedures were performed after approval by the Local Ethics Commission at the University of Medicine, Plovdiv. Every patient was introduced to the study design by the authors, and an informed consent form was signed by the patient or by his guardian/caregiver (in cases diagnosed with intellectual disability) before participation in the study.

The study was performed with the participation of 246 consecutive patients with epilepsy who attended the Clinic of Neurology at the university hospital in Plovdiv, Bulgaria over a period of 2 years of regular examinations or in cases of unsatisfactory seizure control or adverse events from treatment. We used the following inclusion criteria: a signed informed consent form; age between 18 and 65 years; diagnosis of RE; cognitive impairment based on Evaluation rapide des fonctions cognitives (ERFC) [13], with a score of <47 in patients up to 60 years of age and with primary education or <46 in patients between 60 and 65 years of age and with less than a primary education or illiteracy; lack of chronic severe physical comorbidity or progressive neurological disease; lack of a simple or complex partial seizure in the last 4 h; and lack of generalized tonic–clonic seizures in the last 24 h. After excluding 39 patients with pseudorefractory epilepsy (in cases with diagnostic and therapeutic errors or poor adherence), 2 patients older than 65 years, 1 patient with a progressive neurological disease, 3 patients with a simple or complex partial seizure in the last 4 h or a generalized tonic–clonic seizure in the last 24 h, 69 patients with refractory epilepsy without cognitive problems, 68 patients with pharmacosensitive epilepsy, and 64 patients with RE and cognitive problems who fulfilled the inclusion criteria remained in the study. We accepted epilepsy as refractory in cases in which adequate seizure control had not been achieved with at least 2 potentially effective antiepileptic drugs prescribed as monotherapy or polytherapy at maximal tolerated doses. The selection of patients was performed by a neurologist who is a specialist in epilepsy.

The ERFC contains 12 subscales that are completed in approximately 15 min – orientation in time and space, attention and memory, calculation, reasoning and conclusions, understanding, naming, repetition, written command execution, naming, praxis, visual decoding, and writing. The questionnaire has satisfactory test–retest reliability ($r = 0.87$) and very good validity (strong correlation with the Mini Mental State Examination – $r = 0.97$) [13]. The maximum score is 50. We accepted mild cognitive impairment in cases with an ERFC score of 36–46/47, moderate – in cases with a score of 17–35, and severe – in cases with a score of less than 17.

We determined the correlations between enacted stigmatization and demographics (age and gender), degree of cognitive impairment, clinical findings (seizure frequency, seizure type), and perceived stigma. The data were collected by a trained health professional by means of a purposeful interview and examination of the patients' medical documentation.

With the help of their caregivers, 56 patients with mild to moderate intellectual impairment completed the stigma scale [14] and were interviewed about a real experience of discrimination and/or abuse.

The stigma scale for people with intellectual impairment is a ten-item self-report instrument that uses an easy-to-understand format with a large font and accompanying photographs illustrating the statements and takes 5–10 min to complete. It was developed by Ali et al. with the detailed input of professionals working with people with intellectual disability, individuals with intellectual disability, and caretakers [14]. The 'yes/no' format is readily understood. Participants with moderate intellectual impairment sometimes require additional support. The test has an acceptable test–retest reliability ($r = 0.74$) and high internal consistency (Cronbach's alpha = 0.84) [14].

The interview about enacted stigma consisted of four statements about a real experience of discrimination (1. I have been discriminated against by institutions, e.g., police, public administration institutions, and health-care institutions; 2. I have been discriminated against in education; 3. I have been discriminated against by employers; 4. I have been discriminated against by family) and two statements about a real experience of insults, threats, and attacks (1. I have been insulted because of my health problems; 2. I have been threatened and/or attacked because of my health problems). The meaning of every question was explained in detail for the purpose of obtaining adequate answers. We assessed enacted stigma in its two aspects (discrimination and a real experience of insults, threats, and attacks) by calculating the total number of positive answers for each patient.

Data were processed using STATA version 10 (Stata Corp., College Station, TX, USA) and SPSS (Statistical Package for the Social Sciences) version 14.0 (SPSS Inc., Chicago, IL, USA). The results for quantitative variables are expressed as means \pm SE (standard error) and the results for qualitative variables as percentages. The index of stigma was the principal outcome. The association of stigma with demographics, degree of cognitive impairment, mental status, and clinical findings was tested by means of χ^2 -tests and F-tests. The complex influence of the significant demographics, clinical findings, and perceived stigma was determined by multivariate regression analysis. The level of significance was set at $P < 0.05$.

3. Results

Thirty-two (50%) participants in our study were men; the remaining 32 participants were women. Their age range was from 19 to 65 years, and the mean age was 44.88 ± 1.84 years. The clinical findings and degree of cognitive impairment are shown in Table 1.

Only the patients with severe cognitive impairment had an actual diagnosis of intellectual disability. In all other participants, the cognitive impairment was viewed as secondary to epilepsy.

The results from the stigma scale are reported item by item in Table 2. The most frequent reasons for perceived stigma were perceptions about some type of "wrong" attitude of people that worry patients and make them feel embarrassed. In a comparatively small number of

Table 1
Clinical findings and the degree of cognitive impairment of patients with RE and cognitive problems.

	N	P (%)	SE
Type of seizures			
Partial	6	9.37	3.67
Generalized	22	34.38	5.98
Polymorphic	36	56.25	6.25
Cognitive impairment			
Mild	21	32.81	5.92
Moderate	35	54.69	6.27
Severe	8	12.50	4.17
Recent seizure frequency			
No seizures in recent years	5	7.81	3.38
1–11 seizures/year	4	6.25	3.05
High seizure frequency (per month, per week, and daily)	55	85.94	4.38

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