

THE SECOND STEP IN THE CONSTRUCTION OF A STIGMA SCALE OF EPILEPSY

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ABSTRACT - Rationale: The issue of stigmatization is one of the most common psychosocial problems faced by people with epilepsy. **Purpose:** A second step towards the development of a scale to measure epilepsy stigma. **Method:** We applied a closed questionnaire to 12 patients and 32 relatives from the Epilepsy Outpatient Clinic at the University Hospital of Campinas. **Results:** The results are grouped in three main domains: medical, social and personal areas. Medical: the subjects did not know exactly what epilepsy is or how it is caused; nonetheless they know how to treat it. Social: the most important areas that people with epilepsy are discriminated are at work and social relationships. Patients also complained about their lack of freedom and limits on recreation activities. Personal Area: subjects apparently have the same feelings and thoughts about epilepsy and seizures. **Conclusion:** This study analyzed the most common aspects presented in the questionnaire to assess epilepsy stigma for the Brazilian culture which are the base to the elaboration of a stigma scale of epilepsy.

KEY WORDS: stigma, epilepsy, scale, quality of life, seizures.

O segundo passo para a construção de uma escala de estigma na epilepsia

RESUMO - Introdução: O estigma tem sido projetado como um dos problemas sociais mais comuns enfrentados por pessoas com epilepsia. **Objetivo:** Este estudo representa o segundo passo no desenvolvimento da escala para mensurar estigma na epilepsia. **Método:** O questionário foi aplicado em 12 pacientes e 32 familiares, entrevistados no Ambulatório de Epilepsia do Hospital das Clínicas, UNICAMP. **Resultados:** Os resultados estão agrupados nas três principais áreas: médica, social e pessoal. Médica: os sujeitos mostraram não ter informação suficiente ou adequada sobre epilepsia e crises, o que não aconteceu com relação ao tratamento. Social: o trabalho e as relações sociais apareceram como os aspectos de maior discriminação na epilepsia. Os pacientes também ressaltaram a falta de liberdade e restrição de atividades de lazer como aspectos bastante prejudicados. Área pessoal: todos os sujeitos aparentemente têm os mesmos sentimentos e pensamentos sobre epilepsia e crises epiléticas. **Conclusão:** Este estudo analisou os aspectos mais comuns apresentados no questionário para avaliar o estigma na epilepsia na cultura brasileira, os quais serão a base da elaboração da escala de estigma na epilepsia.

PALAVRAS-CHAVE: estigma, epilepsia, escala, qualidade de vida, crises epiléticas.

Epilepsy is a common neurological condition that affects the psychological adjustment and the quality of people's life and therefore reveals a high incidence of fears, misunderstanding and stigma^{1,2}. The social and psychological consequences of epilepsy are numerous. Patients often describe social stigma and the fear of being discriminated³. The issue of stigmatization is one of the most common psychosocial problems faced by people with epilepsy⁴⁻⁹. The stigmatization may lead to social withdrawn, problems at work and home, and economic difficulties.

Awareness about epilepsy is usually very low

across the world. This can often lead to public discrimination and exclusion of people with epilepsy, as well as inappropriate treatment¹⁰. The identification of the people with epilepsy's needs and the promotion of public and professional education about this condition would offer to the patient a greater quality of life in terms of feeling better. It is apparent that medical management of epilepsy alone is not always enough to control its psychological consequences. Services that enable people to deal with negative reactions and which facilitate a realistic perception of the limitations imposed by the

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condition may contribute substantially to the reduction of stigma and the improvement of quality of life¹¹.

Our former study¹² has discussed the importance of creating a specific instrument to assess epilepsy stigma for the Brazilian culture. The first step was an exploratory study towards elaboration of a stigma scale based on results from a comprehensive review on this theme to conceptualize the main domains of epilepsy stigma. Three main domains were observed: medical, personal and social. The first open questionnaire was important to raise the first reactions about the concepts of epilepsy and stigma¹². This study represents a second step towards the development of a scale to measure epilepsy stigma. We are now looking for the most common aspects presented in the questionnaire, which are going to be used in the elaboration of the stigma scale of epilepsy.

METHOD

Subjects – This study focused on patients and their relatives from the Epilepsy Outpatient Clinic at the University Hospital of Campinas, Brazil. Twelve adult patients and thirty-two relatives were interviewed. There were 13 men and 31 women.

Instruments – The questionnaires used in this study came from the open questionnaire of our former study¹². The questionnaire used for the community had 16 closed questions about the medical (4 questions), social (10 questions) and personal (2 questions) areas. The patients' questionnaire had four additional questions in the social and three in the personal area. The answers were categorized and could have multiple responses.

Assessment – Patients and relatives were interviewed by psychologists (PTF, PCBS, FDB) at the Epilepsy Outpatient Clinic of University Hospital of State University of Campinas. The questionnaires were individually applied, and the condition was the same for all the subjects. The application took about 20 minutes. All subjects had signed the Informed Consent, approved by the Ethics Committee of Unicamp (number 064/2002).

RESULTS

The mean age of the patients was 27 years (range from 12 to 42). The mean age of the relatives was 47 years (range from 27 to 66). Half of the interviewers had not completed elementary school.

The results are grouped in three main domains: medical, social and personal areas. The most common answers given by patients and their relatives during the entire questionnaire are shown on Tables 1, 2 and 3. The whole questionnaire is presented on these tables, divided in domains. The answers showed are the most common ones that mean the ones with a frequency higher than 50%, which are going to be the base to the scale elaboration.

The main findings for each domain are the following: i) in the medical area both patients and relatives did not know exactly what epilepsy is or how is it caused, nonetheless they know how to treat it. ii) in the social area both patients and relatives agree that the most important areas that people with epilepsy face difficulties and are discriminated are at work and social relationships. Patients seem not to understand why this discrimination occurs, but their relatives said they would never hire anyone with epilepsy because of prejudice, fear, risks, and difficulty to deal with seizures. Patients also complained about their lack of freedom and limitations on recreation activities. iii) in the personal area patients and relatives apparently have the same feelings and thoughts about epilepsy and seizures.

DISCUSSION

This study, as a second step to the elaboration of a stigma scale, focused on the most common aspects presented in this questionnaire to assess epilepsy stigma for the Brazilian culture. The results showed that patients and their relatives did not have enough or adequate information about epilepsy and seizures, which may be a factor leading to stigma. Patients seem to feel that epilepsy disturbs their lives in some aspects that are not recognized or in-

Table 1. Medical area.

Questions	Patients	Relatives
What is epilepsy?	Convulsion, headache, disease	Convulsion, headache, faint
What are the causes of epilepsy?	I do not know, trauma	I do not know
What do you know about the types of treatment for epilepsy?	Medication, exams, surgery	Medication, exams
How did you get this information?	Doctors, school	Doctors, television

Table 2. Social area.

Questions	Patients	Relatives
Do you know anyone who has epilepsy?	–	Yes
What would you do if you see someone having a seizure? What people do when you have a seizure?*	Help, shock	Help
Which are the difficulties faced by people with epilepsy?	Work, no freedom	Social relationships, work
In what situations do you think a person with epilepsy is discriminated?	Religion, social relationships, work, recreation activities	Work, social relationships, most of the situations
Do you think it is more difficult to a person with epilepsy to find work? Why?	Yes. Prejudice, risks	Yes. Prejudice, risks
What is your religion and what does it think about epilepsy?	Catholic. It is a neurological condition, I do not know	Catholic. It is a neurological condition, I do not know
Would you hire someone with epilepsy to work at your house?	Yes. They are normal people, they have the same rights	No. Prejudice, fear, risks, difficulty to deal with seizures
Would you marry someone with epilepsy? Why?	Yes. They have the same rights, they are ordinary people	Yes. They have the same rights, they are ordinary people
Do you think people with epilepsy can drive? Why?	No. Risks	No. Risks
Would you allow some close to you to have a friend with epilepsy? Why?	Yes. They have the same rights, they are ordinary people	Yes. They have the same rights, they are ordinary people
Do you feel your doctor take care of you? *	Yes.	–
What do you do when you feel you are about to have a seizure?*	Sit or lay down, get nervous, nothing	–
Do you tell people about your epilepsy? *	Yes	–

*only for patients

Table 3. Personal area.

Questions	Patients	Relatives
How do you feel when you see a seizure?	Afraid, sad, nervous	Sad, afraid, pity
How do you feel when you have a seizure? *		
How do you think people with epilepsy feel?	Insecure, sad, worried,	Insecure, sad, worried,
How do you feel among others? *	normal	shamed
What do you guess people think of you when you have a seizure?*	I am not healthy, prejudice, fear, pity	–

*only for patients.

interpreted in a different way by their family. This was clear in the Social Domain, whereas people with epilepsy would hire someone with epilepsy, because they view themselves as normal people who have the same rights. However, their relatives disagree and pointed out prejudice, fear, possible risks and

difficulties to deal with seizures in a working environment. These answers in part reflect overprotection, a common pattern observed in pediatric groups, but also it can be a realistic view of patients with frequent and severe seizure in one extreme to pure simple prejudice in the other.

Attention should be paid for the fact that society was represented in this study by patients' relatives, that is, people who are used to live with "epileptics". We believe the wrong ideas about epilepsy and the discriminative feelings found in this study would be even stronger when taking the society as a whole.

In a psychological view, the judgment of "epileptics", based on inadequate information and beliefs, reinforces the feeling of impotence that patients have about their seizures and themselves. Because people with epilepsy have so often internalized society's devaluation of them, they do not think they can change the situation. Indeed, negative stereotypes of people with epilepsy have been so ingrained in the collective belief system that they have become an accepted part of many people's concept of the disorder¹³, including patients themselves. They may feel and be discriminated, but they do not believe in changing this situation. These aspects have a great impact on the felt stigma and make it difficult to distinguish felt and enacted stigma.

There has been an increasing recognition that seizures might be less disabling than their psychosocial correlates. It has been assumed that the main threat comes from "normal" people who, ignorant and apprehensive about what epilepsy is, tend to maintain social distance through discriminatory practices in both public and private spheres¹⁰.

Medical management of epilepsy clearly has impact on psychological outcome as well as stigma. Nevertheless, at this point, our objective was centered on perception of epilepsy by patients and society. The development of an instrument based on this study can provide a quantitative measurement

of stigma, and then future researches involving stigma and others correlates, as epilepsy (age at seizure onset, seizures type and frequency, antiepileptic drugs, and others) and social (social and school level, civil status, and others) data can be analyzed.

In conclusion, the answers obtained in this study provided a clue based on the specific domains (medical, social and personal) about felt and enacted stigma, however, a larger sample in a community can complement the understanding of stigma and shortlist the most important points to be used in a stigma scale of epilepsy.

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