

STIGMA AND ATTITUDES ON EPILEPSY

A study with secondary school students

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ABSTRACT - Purpose: To evaluate whether an inappropriate attitude towards a person having an epileptic seizure contributes to the stigma found in society and whether an appropriate attitude helps to diminish it in the short term; to perform a long term investigation about information remembered and stigma perception after an educational lecture. **Method:** This study was performed in two steps: Step 1. Students of first year of high school of two schools in Campinas completed a questionnaire including the Stigma Scale of Epilepsy following a seizure demonstration. They were divided into three groups: a) one group had a demonstration of proper attitudes towards someone having an epileptic seizure; b) one group was shown incorrect procedures; c) control group. After the completion of the questionnaire, an educational lecture about epilepsy was given. Step 2: six months later, the questionnaire was re-administered. **Results:** The comparison between the four groups (step 1 and step 2) show a significant difference (Anova (3,339)=2.77; p=0.042). Pairwise comparison using Fisher's Least-Significant-Difference Test showed a significant difference between the group shown incorrect procedures (step 1) versus step 2, and the control group (step 1) versus step 2, but no difference between the group shown correct procedures (step 1) versus step 2. **Discussion:** Exhibiting proper attitudes towards a person experiencing an epileptic seizure may cause significant differences among the subjects' degrees of stigma towards people with epilepsy. It is therefore fundamental that there should be de-stigmatization campaigns provided, to correct information and provide appropriate education.

KEY WORDS: stigma, epilepsy, attitudes, behaviour, quality of life.

Atitudes e estigma na epilepsia: um estudo com jovens do ensino médio

RESUMO - Objetivo: Investigar se atitudes errôneas tomadas durante uma crise epiléptica contribuem para o estigma na sociedade e, se a conduta de seguir atitudes corretas ajuda a diminuir-lo a curto prazo e se a participação em palestra informativa também contribui para a diminuição do estigma a longo prazo. **Método:** O trabalho foi realizado em duas etapas: 1. Foi aplicada a Escala de Estigma na Epilepsia (EEE), acrescida de algumas perguntas gerais sobre epilepsia, em alunos do primeiro ano do Ensino Médio de duas escolas (pública e particular) em Campinas. Os sujeitos foram divididos em 3 grupos, sendo: a) grupo que presenciou atitudes corretas durante a crise epiléptica; b) grupo que presenciou atitudes errôneas durante a mesma; c) grupo controle que só respondeu ao questionário, e depois, todos foram reunidos para palestra educativa. 2. Depois de seis meses, o mesmo questionário foi aplicado nos sujeitos que participaram da palestra educativa da primeira etapa. **Resultados:** A comparação entre os quatro grupos (passo 1 e 2) mostrou diferença significativa [(ANOVA (3,339)=2,77; p=0,042). Análise estatística (Fisher) mostrou diferenças significativas entre o grupo que presenciou atitudes incorretas (etapa 1) e a etapa 2, entre o grupo controle (etapa 1) e a etapa 2, e não encontrou diferenças entre o grupo que presenciou atitudes corretas (etapa 1) e a etapa 2. **Discussão:** Os sujeitos expostos a condutas adequadas durante uma crise epiléptica, bem como a informações corretas sobre epilepsia demonstraram menor percepção de estigma. Com isso, concluímos que intervenções educacionais devem ser realizadas para se tentar mudanças a longo prazo.

PALAVRAS-CHAVE: estigma, epilepsia, atitudes, comportamento, qualidade de vida.

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Epilepsy is a neurological condition characterized by recurrent epileptic seizures without toxic-metabolic or febrile cause. Around 1% of the Brazilian population¹ has epilepsy. In addition to seizures, epilepsy has important psycho-social impact on patients' lives².

As in other chronic conditions, epilepsy has emotional and social health implications in addition to its physical effects³, requiring those with epilepsy to adapt to social environments, and to deal with emotional difficulties.

People with epilepsy report psychological difficulties, social isolation and stigma perception, leading to psychosocial disturbances and quality of life impairment^{4,5}. Subjective influences are of great importance for the well-being of the person with epilepsy; the affective and cognitive meaning that the individual attributes to the condition may determine subsequent feelings and behaviours³. In a chronic disease, the self-evaluation of the meaning of "being sick" and the development of strategies of psychological adaptation are fundamental for the establishment of general well-being³.

It is important to highlight factors that influence the quality of life in epilepsy, such as the social support received⁶, emphasising the importance of making society conscious of epilepsy. Moreover, the quality of life of people with epilepsy is also related to other aspects, such as socio-economic conditions, the frequency and severity of seizures, side-effects of antiepileptic medications and attitudes from those with whom they live, from society and themselves⁴.

Furthermore, in many cases the stigma associated with epilepsy is more harmful than the condition itself^{2,4,7}. A recent study⁴ showed that epilepsy stigma could be caused by lack of adequate information, by inappropriate attitudes and behaviours, and by the social impact of epilepsy. People with epilepsy are more exposed to inappropriate attitudes⁸, experiencing stigma even in childhood, and sometimes from within their own families. Higher levels of stigma perception have been shown to be associated with lower levels of self-efficacy in dealing with epilepsy, poorer results from treatment, less adherence to the treatment regimen and low satisfaction as patients⁹.

The way in which others react towards a person having an epileptic seizure may influence the perception of epilepsy stigma. In Brazil many people, including physicians, nurses and other healthcare personnel, do not know how to react to a person having a seizure^{4,5,9}. Furthermore, the correct understanding about the nature of epilepsy and how to proceed

during an epileptic seizure may determine the way in which people with epilepsy will be treated by society^{4,5}.

This study is a part of phase IV of the Demonstration Project on Epilepsy in Brazil, part of WHO/ILAE/IBE Global Campaign Against Epilepsy, executed by ASPE, Assistência à Saúde de Pacientes com Epilepsia¹⁰. The objectives of this study were: 1. to evaluate whether an inappropriate approach to a person experiencing an epileptic seizure contributes to stigma in society, and conversely whether the correct approach helps to decrease it in the short term; 2. to perform a long-term investigation about any change in knowledge and stigma perception after an educational lecture.

METHOD

This study was performed in two steps.

Subjects

Step 1 – Three classes of approximately equal numbers of students of fifth graders from one public and one private secondary school in the city of Campinas were studied. The school routine consisted of a total of five classes with a break after the third class. In order to avoid cross talk among the classes the experiment was conducted before the break. The classes were randomly selected and the experiment took place in the following order:

- Group 1: An actor simulated a generalized tonic-clonic seizure and students in this group were shown the correct procedures to follow in assisting a person experiencing a seizure.
 - Group 2: An actor simulated a generalized tonic-clonic seizure, and students were shown inappropriate and biased procedures for dealing with a person having a seizure.
 - Group 3: Students in the control group did not see the simulation and received no information.
- All the subjects then completed a questionnaire.

Step 2 – Six months later, the questionnaire was completed again by participating students.

Instrument

A questionnaire including the Stigma Scale of Epilepsy (SSE)^{4,5} was used; the SSE investigates people's perceptions and attitudes towards epilepsy, providing a measure of stigma perception that varies between 0 (no stigma) and 100 (a higher stigma perception). In addition to the SSE, the following questions were included: *Have you received any information about epilepsy? What types of epilepsy treatment do you know? What attitudes do you think that people with epilepsy have?*

Procedure

Step 1 – The procedure was the same in both schools. A researcher (BAR) was introduced as a medical student

at the Medical School of the University of Campinas (Unicamp). A generalized tonic-clonic seizure was simulated by an actor to groups 1 and 2. The researcher demonstrated the way in which the students should act if they witness a seizure, following pre-established scripts:

- Group 1 was shown the correct procedure: to remain calm, to protect the patient's head and turn it to one side, to remove any nearby objects that could hurt them, to wait for the seizure to end and to talk to the patient.
- Group 2 was shown incorrect procedures: the researcher put a pen in the patient's mouth, tried to pull the tongue (saying that there is a risk of swallowing it), told the students to avoid being contaminated by saliva, and instructed them to contain the patient's movements.

At the end of the demonstration, the questionnaire was completed by the students in groups 1 and 2; taking around 15 minutes.

- Group 3 students were only asked to complete the questionnaire.

The students were unable to exchange information before completion of the questionnaire. After the questionnaire had been completed the researcher gave an educational lecture on epilepsy (lasting approximately 30 minutes) to all three groups; covering the following subjects:

- The nature and possible causes of epilepsy.
- Seizures: Main types and general considerations.
- Epilepsy treatment.
- Myths and truths about epilepsy.
- Correct procedure if students witness an epileptic seizure.

The actor again demonstrated a seizure and the re-

searcher gave the correct information on how to act during it.

After the lecture, time was allowed for clarification of students' doubts and questions on the subject. As well as the students, some teachers and other workers from the schools who attended the lecture were able to clarify doubts. The most frequent questions related to sports, walking and leisure activities, women's care, drugs and the behaviour of people with epilepsy.

Step 2 – Approximately six months after the educational lecture, the students were asked to complete the SSE questionnaire again. Only students available at the time completed questionnaires.

RESULTS

Step 1 – One-hundred and eight-two SSE questionnaires were completed - 97 by public school students and 85 by private school students (Table 1). The demographics of the subjects are shown on Table 2.

Table 3 shows the subjects' answers to the SSE questions, using a scale between 1 and 4 (1=no, 2=a little, 3=a lot, 4=very much), used for the calculation of the general score of stigma perception.

The general score of epilepsy stigma obtained through the SSE was 45.5 for the public school and 43.3 for the private school ($p>0.05$). Figure 1 illustrates the scores obtained (*least squares means*) by the different groups, showing a significant difference among the general scores in the three groups.

Table 1. Number of subjects by group and school.

	Public school	Private school
Group 1 (correct procedure)	32	26
Group 2 (incorrect procedure)	35	27
Group 3 (no demonstration)	30	32
Total	97	85

Table 2. Characterization of subjects.

	Public school (%)	Private school (%)
Sex		
Male	55.7	57.6
Female	44.3	42.4
Average age (years)	15 (SD=0.71)	15 (SD=0.52)
Religion		
Catholic	60.8	49.4
Evangelical	17.5	8.2
Spiritist	0	11.8
Others	20.6	10.6
None	1.0	20.0

The numbers are presented in percentage, excepting the ages, which are presented in absolute values, n=182.

Table 3. Subjects' perception about epilepsy (SSE).

	No			A little			A lot			Very much		
	G1	G2	G3	G1	G2	G3	G1	G2	G3	G1	G2	G3
Do you think that people with epilepsy feel able to control their own epilepsy?	00.0	1.6	0.00	1.7	3.2	1.6	19.0	21.0	29.0	79.3	74.2	69.4
How do you feel when you see an epileptic seizure?												
Frightened	14.3	3.2	21.3	35.7	37.1	37.7	23.2	37.1	26.2	26.8	22.6	14.8
Scared	32.7	33.9	59.1	52.7	38.7	21.3	9.1	12.9	14.7	5.5	14.6	4.9
Sad	45.6	31.3	34.4	29.8	37.8	34.4	10.6	19.7	21.3	14.0	11.5	9.8
Pity	37.5	32.8	42.6	37.5	41.0	31.2	10.7	16.4	16.4	14.3	9.8	9.8
Which difficulties do you think people with epilepsy have in their daily life?												
Relationship	69.0	54.8	62.9	22.4	27.4	32.3	8.6	14.5	1.5	0.0	3.4	3.3
Work	13.8	3.3	9.7	50.0	37.1	40.3	24.1	27.4	30.6	12.1	32.3	19.3
School	34.5	14.5	22.6	39.7	45.2	45.2	22.4	27.4	24.2	3.4	12.9	8.1
Friendship	39.7	25.8	24.2	32.7	29.0	35.5	15.5	27.4	24.2	12.1	17.7	16.1
Sexual	44.8	22.6	45.2	34.5	29.0	25.8	10.3	30.6	17.7	10.3	17.7	11.3
Emotional	13.8	12.9	11.3	34.5	33.9	27.4	32.7	29.0	29.0	19.0	24.2	32.3
Prejudice	15.5	12.9	4.8	24.1	22.6	25.8	37.9	27.4	32.3	22.4	37.1	37.1
How do you think that people with epilepsy feel?												
Worried	12.1	6.4	6.6	34.48	30.7	44.3	37.9	46.7	34.4	15.5	16.2	14.7
Dependent	33.3	19.4	26.2	42.1	50.0	39.3	19.3	17.7	24.6	5.2	12.9	9.8
Incapable	43.9	43.6	41.0	35.1	30.6	31.2	17.5	22.6	16.4	3.5	3.2	11.4
Afraid	24.1	14.5	18.3	43.1	37.1	36.7	24.1	30.7	31.7	8.6	17.7	13.3
Ashamed	23.2	24.6	10.0	37.5	42.6	41.7	17.9	23.0	25.0	21.4	9.8	23.3
Sad	35.7	12.9	20.0	41.1	51.6	26.7	17.9	22.6	35.0	5.46	12.9	18.3
Equal	14.1	8.1	13.1	24.6	8.1	9.8	33.3	37.1	31.2	28.0	46.8	45.9
In your opinion, in which situation does prejudice against epilepsy occur?												
Relationship	8.6	11.3	11.7	39.7	45.2	48.3	29.3	25.8	31.7	22.4	17.7	8.3
Marriage	50.0	50.0	50.0	24.1	35.5	30.7	10.3	11.3	8.1	15.5	3.2	11.3
Work	8.6	6.5	9.7	50.0	38.7	40.3	25.9	33.9	27.4	15.5	21.0	22.6
School	14.0	8.2	4.8	43.9	50.8	43.6	29.8	24.6	32.3	12.3	16.4	19.4
Family	75.4	75.8	61.3	22.8	11.3	30.6	0.0	3.2	4.8	1.8	9.7	3.2

The numbers are presented in relative percentage among the groups, by line.

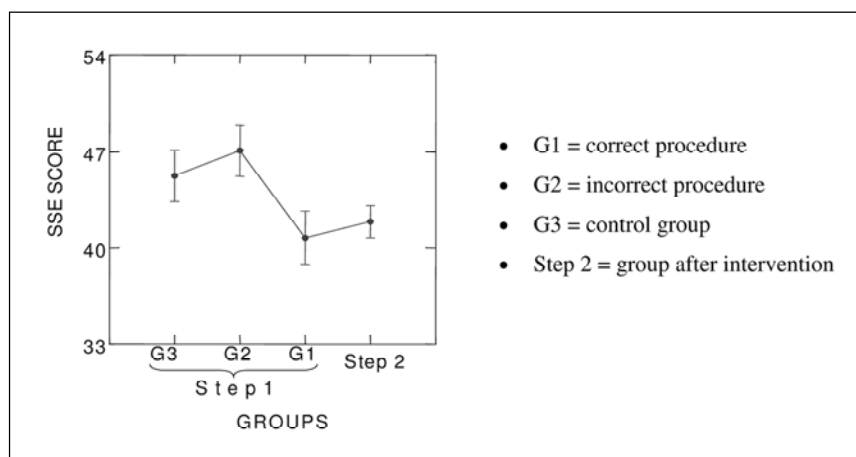


Fig 1. General score obtained through the SSE from the schools in two steps.

Table 4. Data related to information.

	No			A little			A lot			Very much		
	G1	G2	G3	G1	G2	G3	G1	G2	G3	G1	G2	G3
Do you have any information about epilepsy?	44.8	54.1	60.0	46.5	44.3	36.7	8.6	1.6	3.3	0.0	0.0	0.0
What types of epilepsy treatment do you know?												
Neurological	6.9	11.5	19.3	22.4	22.9	30.7	44.8	36.1	30.7	25.9	29.5	19.4
Psychological	5.3	16.7	14.5	49.1	41.7	50.0	33.3	33.3	30.7	12.3	8.3	4.8
Spiritual	49.1	64.4	71.0	40.4	25.4	21.0	10.5	3.4	6.5	0.0	6.8	1.6
Psychiatric	22.8	33.3	40.3	52.6	43.3	38.7	14.0	16.7	16.1	10.5	6.7	4.8
Which attitudes do you think people with epilepsy have?												
They tell other people about their epilepsy	50.9	54.1	61.7	43.9	41.0	31.7	3.5	3.3	3.3	1.8	1.6	3.3
They look for treatment	5.2	0.0	8.2	25.9	29.5	37.7	34.5	32.8	37.7	34.5	37.7	16.4
They isolate themselves	38.6	39.3	31.2	43.9	42.6	49.2	14.0	11.5	13.1	3.5	6.6	6.6
They act normally	19.3	24.6	21.7	42.1	29.5	38.3	17.5	29.5	33.3	21.1	16.4	6.7

The numbers are presented in relative percentage among the groups, by line.

Table 4 shows data relating to questions about epilepsy information.

Step 2 – Six months after the lecture, 86 SSE questionnaires were completed (65 students from the private school and 21 from the public school) constituting only one group of study. In the private school, sixty-three percent (63%) of the students were female, average age 16 years, and in the public school, seventy-six percent (76%) were female, average age 16 years.

The average general SSE score at this step was 44.5.

The comparison between the four groups (step 1 and step 2) are presented in the Figure 1 (Anova (3,339)=2.77; p=0.042). Pairwise comparison using Fisher's Least-Significant-Difference Test showed a significant difference between G2 (the group shown incorrect procedures in step 1) versus step 2 (six months later), and between G3 (the control group) versus step 2, but no difference between G1 (the group shown the correct procedure in step 1) versus step 2.

DISCUSSION

This study concerns information and attitudes of students towards people with epilepsy. We conclude that the perception of epilepsy stigma is higher in the group that received inappropriate education about reacting to an epileptic seizure. We showed that the influence and perpetuation of stigma were greater in the group exposed to erroneous attitudes

(Group 2). Answers demonstrating lack of knowledge and increased stigma also seemed to be associated with group 2. This may suggest that, in addition to the transmission of correct information, emphasis on correct attitudes is fundamental. This is because the stigma process is facilitated by inappropriate social behaviours^{4,5,11}. We know that society's attitudes and behaviours can be more adverse than the seizures themselves, in causing negative impact on the patients' daily lives¹¹.

Comparing the two steps, the results showed that the stigma perception changed over time. This may indicate that information and attitudes working together are capable of reducing the perception of epilepsy stigma in the long term. After the intervention (step 2), the subjects showed a retention of knowledge and of the correct way to behave when witnessing a seizure. Furthermore we noted from comments of participants that it seems easier for people to remember scenes than words. The visual memory may have greater impact for acquisition of concepts about stigma perception, and the information given through the lecture was not remembered as well as the seizure visualization; it seems not to have been effective in changing attitudes. The practical demonstration of a seizure with the appropriate information may have had a major impact in altering previously learned behaviour about dealing with seizures.

As shown previously^{2,4,5,11-16}, stigma aetiology is related to several factors; the lack of information

associated with the non-control of seizures, the uncertainty regarding prognosis and the social impact of epilepsy are important aspects in the determination of stigma, taking into account the fact that lack of information and negative attitudes towards epilepsy constitute the main factors for the determination of this stigma⁴. The de-stigmatization campaigns in schools should therefore emphasize these two aspects in order to obtain a significant improvement in the quality of life of people with epilepsy.

Therapeutic efforts towards the control of seizures are not enough. This study confirms that people with epilepsy and their families need more than medical treatment in order to have a better quality of life¹⁷.

A recent study of a psycho-educational intervention for adolescents with epilepsy and their families showed its importance for their needs, helping them to have a better understanding of their epilepsy, and the results showed an improvement of these adolescents' quality of life¹⁸. Another study¹⁹ showed that many elementary school teachers do not have the necessary knowledge about epilepsy and therefore they deal with students with epilepsy in an inappropriate way. In the current study a similar situation occurred.

The acquisition of information with the demonstration of appropriate attitudes concerning a disease or condition is able to influence the change in perception of pre-established prejudices and beliefs²⁰, contributing to the non-increase of stigma perception within society.

We feel, therefore, that we now have some evidence that correct information and the demonstration of appropriate attitudes are important aspects in dealing with social stigma. One important aspect is the way in which this information is transmitted (visual or verbal, for example the simulation of an epileptic seizure) to improve people's attitudes towards people with epilepsy.

It is therefore fundamental that de-stigmatiza-

tion campaigns should be provided continuously, as this may help to get people with epilepsy out of the shadows.

REFERENCES

1. Noronha ALA, Borges A, Marques LH, et al. Prevalence and pattern of epilepsy treatment in different social-economic classes in Brazil. *Epilepsia*, **(*)1-6, 2007, doi:10.1111/j.1528-1167.2006.00974.
2. Baker GA. The psychosocial burden of epilepsy. *Epilepsia* 2002;43(Suppl 6):26-30.
3. Souza EA, Salgado PC. Qualidade de vida em epilepsia e percepção de controle de crises. *Arq Neuropsiquiatr* 2001;59:537-540.
4. Fernandes PT, Li LM. Estigma na epilepsia. 1-207. 2005. Departamento de Neurologia - FCM/UNICAMP. PhD Thesis.
5. Fernandes PT, Salgado PC, Noronha ALA, Barbosa FD, Souza EA, Li LM. Stigma scale of epilepsy: conceptual issues. *J Epilepsy Clin Neurophysiol* 2004;10:213-218.
6. Souza EA, Fernandes PT, Salgado PC, Doretto F. Mecanismos psicológicos e o estigma na epilepsia. *Revista ComCiência* 2002;34:98-103.
7. Vickroy BG, Hays RD, Graber J, Rausch R, Engel J, Jr., Brook RH. A health-related quality of life instrument for patients evaluated for epilepsy surgery. *Med Care* 1992;30:299-319.
8. Dell JL. Social dimensions of epilepsy, stigma and response. In Whitman S, Hermann BP (Eds). *Psychopathology in epilepsy: social dimensions*. New York: Oxford University, 1986.
9. Li LM, Fernandes PT, Noronha AL, et al. Demonstration project on epilepsy in Brazil: situation assessment. *Arq Neuropsiquiatr* 2007; 65(Supl 1):5-13.
10. Li LM, Sander JW. National demonstration project on epilepsy in Brazil. *Arq Neuropsiquiatr* 2003;61:153-156.
11. Suurmeijer TP, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. *Epilepsia* 2001;42:1160-1168.
12. Baker GA, Brooks J, Buck D, Jacoby A. The stigma of epilepsy: a European perspective. *Epilepsia* 2000;41:98-104.
13. Fernandes PT, Cabral P, Araújo UF, Noronha ALA, Li LM. Kids' perception about epilepsy. *Epilepsy Behav* 2005;6:601-603.
14. Jacoby A, Chadwick D. Psychosocial problems in epilepsy. *BMJ* 1992;305:117.
15. Jacoby A. Stigma, epilepsy, and quality of life. *Epilepsy Behav* 2002;3: 10-20.
16. Salgado PC, Fernandes PT, Noronha ALA, Barbosa FD, Souza EA, Li LM. The second step in the construction of a stigma scale of epilepsy. *Arq Neuropsiquiatr* 2005;63:395-398.
17. Galletti F, Sturmiolo MG. Counseling children and parents about epilepsy. *Patient Educ Couns* 2004;55:422-425.
18. Snead K, Ackerson J, Bailey K, Schmitt MM, Madan-Swain A, Martin RC. Taking charge of epilepsy: the development of a structure psychoeducational group intervention for adolescents with epilepsy and their parents. *Epilepsy Behav* 2004;5:547-556.
19. Prpic I, Korotaj Z, Vlastic-Cicvaric I, Paucic-Kirincic E, Valerjev A, Tomac V. Teachers' opinions about capabilities and behavior of children with epilepsy. *Epilepsy Behav* 2003;4:142-145.
20. Fernandes PT, Noronha AL, Sander JW, Bell GS, Li LM. Training the trainers and disseminating information: a strategy to educate health professionals on epilepsy. *Arq Neuropsiquiatr* 2007;65(Supl 1):14-22.