

EPILEPSY PERCEPTION AMONGST UNIVERSITY STUDENTS

A survey

Juliana Caixeta¹; Paula T. Fernandes^{1,2}, MSc, PhD; Gail S. Bell³, MRCGP, MD, Josemir W. Sander^{3,4}, MD, PhD, FRCP; Li M. Li^{1,2}, MD, PhD

ABSTRACT - Purpose: To evaluate the information that university students have on epilepsy and to compare the differences in attitudes and perception among groups with different levels of information. **Methods:** A questionnaire with 13 questions regarding knowledge, attitudes and perception about epilepsy was completed by first, third and sixth year medical students and to students from Arts and Science courses. **Results:** First year medical students gave inadequate answers, especially with regard to information about epilepsy and actions to take during seizures. Answers of third and sixth year medical students were more adequate. Arts and Science students gave the poorest responses in relation to specialist information and attitudes regarding epilepsy. **Discussion:** This study suggests that there is an inverse relationship between knowledge and stigma on epilepsy. Nevertheless, the best results did not reflect an ideal situation, revealing an urgent need for an improved level of overall health education programs. This can be achieved by implementing educational policies, training programs and the universal inclusion of these subjects in the global educational program.

KEY WORDS: stigma, epilepsy, prejudice.

Percepção de epilepsia em estudantes universitários: uma enquete

RESUMO - Objetivo: Avaliar os conhecimentos de estudantes universitários sobre epilepsia e verificar se há diferenças entre atitudes e percepção em grupos que são submetidos a diferentes graus de informação. **Método:** Foram aplicados questionários contendo 13 questões sobre conhecimentos, percepção e atitudes em epilepsia em alunos da Unicamp, divididos em: primeiro, terceiro e sexto anos de medicina, e alunos de cursos da área de exatas e humanas. **Resultados:** os alunos do primeiro ano de medicina apresentaram muitas respostas inadequadas, principalmente às relacionadas ao conhecimento sobre epilepsia e atitudes durante a crise. Os alunos do terceiro e do sexto ano apresentaram respostas mais adequadas para percepção e atitudes. Os alunos de ciências exatas e humanas apresentaram os piores níveis de resposta para os aspectos de conhecimento técnico e atitudes. **Discussão:** O estudo mostrou que existe uma relação inversa entre conhecimento e estigma. Entretanto, a melhora destes índices não reflete uma condição ideal, existindo a necessidade imediata de melhorar o nível de educação sobre saúde em geral, o que pode ser feito mediante a implantação de políticas educacionais, programas de capacitação e até mesmo da inclusão destes assuntos transversalmente em toda a trajetória de ensino.

PALAVRAS-CHAVE: estigma, epilepsia, preconceito.

Epilepsy is the most common serious neurological condition, affecting approximately 1% of people in the world^{1,2}. Traditionally, the criteria used to assess the condition's impact on the individual's life are exclusively clinical parameters: frequency of seizures, response to treatment, type and severity of the seizures. Currently, an assessment of success also includes the patient's own perception of the difficul-

ties caused by the condition, since social and cultural problems also interfere in quality of life^{3,4}.

Lack of education is likely to be one of the main causes of the stigma related to epilepsy⁵⁻⁷. Even today, dubious comments can often be heard about causes, treatment and consequences of epilepsy in many walks of life.

This study assessing the level of information that

¹Department of Neurology, Faculty of Medicine, UNICAMP, Campinas, SP, Brazil; ²Assistência à Saúde de Pacientes com Epilepsia – ASPE, Campinas, SP, Brazil; ³Department of Clinical and Experimental Epilepsy, UCL Institute of Neurology, London UK; ⁴Epilepsy Institute of the Netherlands, SEIN, Heemstede, Achterweg 5, 2103 SW Heemstede, the Netherlands.

university students at the State University of Campinas (UNICAMP) have about epilepsy and their attitudes and perception regarding this condition was part of phase III of the Demonstration Project on Epilepsy in Brazil, part of WHO/ILAE/IBE Global Campaigning Against Epilepsy, carried out by ASPE⁸.

METHOD

Instrument – The questionnaire, shown in the appendix, consisted of 13 objective questions on epilepsy, including questions related to:

- Students' self-assessment on the information they have about epilepsy (advanced, average, insufficient or none).
- Main source of information on epilepsy (books, physicians, relatives, personal experience, television, scientific meetings).
- Information on epilepsy (cause, treatment, etiology, having witnessed a seizure, knowing a person with epilepsy).
- Attitudes (behavior and attitudes in relation to people with epilepsy).
- Perceptions and feelings (driving vehicles, physical activities, beliefs and feelings regarding seizures).
- Demographic data (age, sex, course) was also collected.

Table 1. Distribution of the subjects according to the course being studied.

Group	Course	N
1	1 st year Medical	65
2	3 rd year Medical	52
3	6 th year Medical	37
4	Sciences (Science)	47
5	Human Sciences (Arts)	47

Subjects – Undergraduate students at the State University of Campinas, UNICAMP, divided into the following groups:

- Group 1: First year medical students.
- Group 2: Third year medical students (who had completed the neurosciences module).
- Group 3: Sixth year medical students (who completed the neurosciences and neurology modules).
- Group 4: Science students reading physics, mathematics, mechanical engineering, or computer science (Sciences).

Table 2. Information about epilepsy.

Answers	Groups				
	1 st yr med N=65	3 rd yr med N=52	6 th yr med N=37	Science N=47	Arts N = 47
Perceived level of information					
Insufficient	61%	11%	27%	52%	61%
Average	26%	77%	67%	41%	34%
Origin of epilepsy					
Neurological	88%	97%	97%	98%	98%
Psychological	6%	2%	0%	0%	4%
Psychiatric	7%	2%	3%	2%	2%
Causes of epilepsy					
Trauma	83%	98%	95%	83%	78%
Fever	37%	35%	43%	15%	17%
Toxic substances	74%	64%	62%	39%	47%
Treatment					
Medication	90%	95%	94%	52%	32%
Surgery	69%	73%	83%	8%	6%
Psychiatric care	25%	29%	32%	2%	10%
Psychological care	15%	18%	8%	14%	16%
Information received from					
Television	15%	13%	13%	19%	38%
Relatives and friends	5%	2%	13%	29%	38%
Personal experience	9%	8%	19%	21%	8%
Physicians	69%	80%	67%	8%	23%
Books	73%	71%	89%	18%	12%

Table 3. Attitudes and feelings.

Answers	Groups				
	1 st yr med	3 rd yr med	6 th yr med	Science	Arts
Action during a seizure					
Protect the head	81%	91%	83%	72%	72%
Place the head sideways	43%	40%	55%	29%	27%
Restrict movement	35%	15%	0%	51%	49%
Pull the tongue	24%	2%	8%	47%	40%
Feelings					
Willing to help	74%	64%	75%	48%	46%
Worried	66%	60%	56%	58%	62%
Impotent	35%	31%	21%	31%	12%
Fearful	18%	0%	2%	8%	12%

Table 4. Perception of epilepsy stigma.

Answers	Groups				
	1 st yr med	3 rd yr med	6 th yr med	Science	Arts
I would marry someone with epilepsy.	82%	91%	89%	63%	68%
I would employ someone with epilepsy.	92%	92%	89%	85%	98%
People with epilepsy					
Have poor cognitive capacity.	3%	3%	8%	0%	6%
Have a higher risk of mental illness.	9%	2%	3%	4%	10%
Should be hospitalized.	0.5%	0%	1%	4%	0%
Should not be allowed to drive.	17%	25%	20%	18%	49%
Have a greater chance of having children with malformations.	6%	8%	13%	8%	4%

- Group 5: Art and Humanity students reading economy, history, social sciences, history, philosophy, arts, languages or literature (Arts).

Procedure – Questionnaires were completed by first year and third year medical students at a time they were sitting an exam. Sixth year medical students carrying out internship activities completed the questionnaires during a lunch break. In the other groups, questionnaires were completed before lectures.

All questionnaires were returned immediately after they were completed. The procedures were the same for all subjects and the questionnaire took around twenty minutes to complete.

RESULTS

Two hundred and forty eight questionnaires were completed. The majority (74%) of the subjects were between 19 years and 22 years old. The groups are shown in Table 1.

The responses are presented regarding the following areas in the questionnaire: 1. Information about epilepsy; 2. Attitudes towards epilepsy; 3. Prejudice (Stigma) towards people with epilepsy.

Information about epilepsy – Table 2 shows selected answers obtained on this item from the different groups.

Attitudes – Table 3 shows students' attitudes and feelings towards epilepsy.

Stigma – Table 4 shows responses regarding stigma attached to epilepsy.

DISCUSSION

This study is important because these undergraduate students are expected to be future professionals in several fields, and are likely to be opinion formers.

First year medical students can be considered to be representative of that part of the population that has attended middle schools providing wholesome education, and are probably mainly from the Brazilian middle class. One interesting finding of this study is these first year students acquired information about epilepsy from physicians and books.

Information on epilepsy and knowledge about actions to be taken during a seizure were judged to be inadequate in view of their replies to the questions. The level of information possessed by these students may be similar to those from the Science and Arts students, although medical students may have a different view of epilepsy since their focus of interest is the individual, diseases and their management.

This study was conducted during the reformulation of the medical curriculum at UNICAMP. This reformulated curriculum aims to produce more humane and ethical physicians who are more aware of the social reality. The implementation of this curriculum started in 2001 and therefore third year students who participated in this study underwent the new curriculum. Hence, it was possible to compare the levels of information and perception of the students from both curricula (as sixth year medical students received the traditional curriculum). Under the new curriculum, students attend lectures on epilepsy in the second year (neuroanatomy and neurophysiology, included in the neuroscience module) that deal with theoretical aspects, clinical cases, videos and discussions on attitudes, prejudice and the social impact of the disease. This resulted in a qualitative improvement, mainly in relation to answers on perception and attitudes, which was similar to or better than the performance of the sixth year students (who had superior knowledge regarding information on epilepsy). Sixth year students had no exposure to epilepsy in the first half of their course and their first contact with epilepsy was in the fourth year, when they attended neurology. Learning through seminars or discussion of outpatient cases preferentially involves clinical aspects (diagnosis, treatment and evolution) to the detriment of discussions on social impact, intervention policies, discrimination and stigma.

Science and Arts students represent future Brazilian professionals without medical training. They can be considered part of the Brazilian intellectual elite as they all face very difficult university entrance examinations (Unicamp has one of the most competitive

entrance exams in the country), have greater access to quality learning and more information than most of the Brazilian population. These two groups, however, showed the lowest levels in relation to technical knowledge and attitudes. These differences would most probably be more accentuated if the general population, with lower educational levels and less access to information, was evaluated and this may also reveal the high degree of stigma associated with epilepsy.

These results show that there is a relationship between the quantity of information and prejudice. The groups with less access to information (first year medical students, and students of human and exact sciences) presented the greatest number of inappropriate answers, especially about how to proceed during an epileptic seizure. Another important fact is the impact caused by the reformulated curriculum that brought students into contact with clinical cases earlier, and raised discussions about social problems. This is probably why the third and sixth year medical students presented very similar results.

Nevertheless, the best results found do not reflect an ideal situation. More information is needed about diverse clinical manifestations so that the students feel confident about dealing with people with epilepsy and are able to combat myths as well as beliefs. Moreover, the possibility that answers were given that were "socially correct" should be considered as they probably explain the high percentage (in all groups) of students who claimed that they would marry individuals with epilepsy although, according to these same students, individuals with epilepsy have a greater chance of developing mental diseases and having children with malformations.

Thus, this seems to suggest that there is an urgent need to improve the level of education in relation to epilepsy. This could be achieved by implementing educational policies, training programs and also by universally including these subjects from the basic educational level (to prevent the occurrence of stigma) right up to university level. Information is one of the best and cheapest instruments used to decrease stigma⁹⁻¹¹ and is a simple and cheap way of successfully improving the quality of life of individuals who manage their own conditions and also have to deal with an excluding, untrained society that limits job possibilities, education and social relationships.

APPENDIX 1 – QUESTIONNAIRE

Dear Students,

This questionnaire is part of a research project that aims at assessing the information that the academic community has on epilepsy. Your answers could help future interventions in the current teaching pattern. We are grateful for your cooperation in answering this questionnaire.

Name (optional): _____

Sex: () F () M Age: _____

Graduation course and year: _____

Date ___/___/___

Please tick in the appropriate brackets. Some questions have more than one answer.

1. How would you assess the information you currently have on epilepsy?
 - () Advanced
 - () Average
 - () Insufficient
 - () None
2. The origin of epilepsy is:
 - () Psychological
 - () Neurological
 - () Psychiatric
 - () Others _____
3. What are the causes of epilepsy?
 - () Headaches
 - () Infections
 - () Cerebral traumas
 - () Bad thoughts
 - () Parasites
 - () Depression
 - () High fever
 - () Complications during childbirth
 - () Toxic substances/medication
 - () Alcoholism
4. What do you think you could do to help an individual having a seizure?
 - () Nothing
 - () Hold the tongue
 - () Throw water on the face
 - () Give the individual something strong to smell
 - () Protect the head
 - () Stay close to the individual
 - () Shake the individual to bring him around
 - () Restrict movements
 - () Place the head on one side
 - () Others _____
5. What do you feel when you see an individual having a seizure?
 - () Frightened
 - () Preoccupied
 - () Indifferent
 - () Pity
 - () Rejection
 - () Desire to help
 - () Impotence
6. What do you know about the treatment for epilepsy?
 - () Medication
 - () Surgery
 - () Psychological care
 - () Psychiatric care
 - () Nothing
 - () Others
7. Do patients with epilepsy have any limitations?
 - () Yes () No
 What? _____
8. Have you ever witnessed a seizure?
 - () Yes () No
9. Is Epilepsy a common disease in a particular social sector?
 - () Yes () No
 Name the sector: _____
10. Do you
 - () Have any relative with epilepsy? Who? _____
 - () Have any close friend with epilepsy?
 - () Know anyone at work/ in class with epilepsy?
11. If you have had access to information on epilepsy, identify the source:
 - () Books/Magazines
 - () Television
 - () Physicians
 - () Relatives and friends
 - () Personal experience
 - () Congresses: () Offered by UNICAMP () Offered by other teaching institutions.

12. Tick the appropriate column.

	Yes	No	Do not know
People with epilepsy			
Are allowed to drive.			
Have fewer work opportunities.			
Can execute any kind of professional activity.			
Would receive better treatment in hospitals.			
Have poor cognitive capacity (learning and memory).			
Have a greater risk of developing mental disorders.			
Have a restricted range of physical activities.			
Can marry.			
Should be enrolled in special schools.			
Can participate in sport activities but with restrictions.			
Can have children.			
Epilepsy			
Is treatable.			
Onset is at any age.			
Is a contagious disease.			
Is more common in some social sectors. Which? _____			
Children of individuals with epilepsy have a greater chance of having malformations.			
You			
Would you marry an individual with epilepsy?			
Would you employ someone with epilepsy to work for you?			
Would you be comfortable relating with people with epilepsy?			
Do you think that more should be done to divulge epilepsy?			

13. Having completed this questionnaire:

() Has your concept of epilepsy remained the same

() Are you more aware of the disease and also aware that you knew less about this disease than imagined.

REFERENCES

- Sander JW, Shorvon SD. Incidence and prevalence studies in epilepsy and their methodological problems: a review. *J Neurol Neurosurg Psychiatry* 1987;50:829-839.
- Saraceno B. The WHO World Health Report 2001 on mental health. *Epidemiol Psichiatr Soc* 2002;11:83-87.
- Fernandes PT, Souza EA. Identification of family variables in parents' groups of children with epilepsy. *Arq Neuropsiquiatr* 2001;59:854-858.
- Guerreiro CA, Guerreiro MM, Cendes F, Lopes-Cendes I. Considerações gerais. In: Lemos Editorial, ed. *Epilepsia*. Sao Paulo: 2000:1-10.
- Ablon J. The nature of stigma and medical conditions. *Epilepsy Behav* 2002;3:2-9.
- Jacoby A. Stigma, epilepsy, and quality of life. *Epilepsy Behav* 2002;3:10-20.
- McLin WM, de Boer HM. Public perceptions about epilepsy. *Epilepsia* 1995;36:957-959.
- Li LM, Sander JW. National demonstration project on epilepsy in Brazil. *Arq Neuropsiquiatr* 2003;61:153-156.
- Fernandes PT, Salgado PC, Noronha AL, Mory SB, Rio PA, Li LM. Combate ao estigma na epilepsia pela conscientização através da mídia. *J Epilepsy Clin Neurophysiol* 2004;10:167-170.
- Fernandes PT, Salgado PC, Noronha AL, Mory SB, Li LM. Formação de grupos como suporte psicológico e social na epilepsia. *J Epilepsy Clin Neurophysiol* 2004;10:171-174.
- Fernandes PT, Li LM. Estigma na epilepsia. 1-207. 2005. Departamento de Neurologia - FCM/UNICAMP. PhD Thesis.