provided by Repositorio da Producao Cientifi

Journal of Epilepsy and Clinical Neurophysiology

J Epilepsy Clin Neurophysiol 2009;15(3):119-122

# Perception and Attitudes Towards Epilepsy: Point of View of Professionals Allied to Medicine from Mobile Emergency Service in Campinas

Paula T. Fernandes\*,\*\*, Ana Lúcia A. Noronha\*,\*\*, José Roberto Hansen\*\*\*, Li M. Li\*,\*\*

Department of Neurology – Faculty of Medical Sciences/State University of Campinas (UNICAMP)

# ABSTRACT

Introduction: Epilepsy is very prevalent in our society, but unfortunately lack of knowledge is still very common, contributing to psycho-social difficulties to people with epilepsy. **Purpose:** The aim of this study was to assess the epilepsy' perception and attitudes by professionals of emergency medical service in Campinas, Brazil. **Material and methods:** This study was carried out with professionals of SAMU-192, who participated on the VII Stroke Workshop of Campinas in November 2007. **Results:** One hundred-forty nine (149) professionals answered the questionnaire (49% women, average age of 37 years, range from 21 to 59 year). Ninety (60%) were professionals allied to medicine (nurses, health auxiliary, dentists), six (4%) were physicians and 53 (36%) were other professions (secretary, driver). In overall, a great majority of the subjects had an appropriate knowledge regarding epilepsy. But, some beliefs are still present. In relation to epilepsy' perception, some wrong ideas appeared, as epilepsy is a contagious disease, people with epilepsy can not practice physical exercise or to work. Also, the doubts regarding pregnancy and treatment of epilepsy were observed. Regarding attitudes during an epileptic seizure, some inadequate attitudes appeared: to put something in patient's mouth, to restrict the patients' movements or give something strong to smell (alcohol or vinegar) in order to stop the seizure. **Conclusion:** In this context, it is necessary a continuous education programs to the allied health professionals to improve the perception and attitudes, bringing epilepsy out of the shadows.

Key words: epilepsy care, medical service, health professionals, education, primary care.

### RESUMO

### Percepção e atitudes sobre a epilepsia: ponto de vista dos profissionais de saúde do Serviço de Atendimento Móvel de Urgência em Campinas

Introdução: Epilepsia é uma condição muito comum em nossa sociedade, mas infelizmente ainda convive com lacunas no conhecimento, contribuindo para dificuldades no ajustamento psicossocial da pessoa com epilepsia. Objetivo: avaliar a percepção e as atitudes dos profissionais de saúde do SAMU-192 sobre a epilepsia. Material e métodos: este estudo foi realizado com profissionais que trabalham no SAMU-192 durante o VII Workshop AVC – Campinas realizado em novembro de 2007, no qual os participantes responderam a um questionário estruturado sobre epilepsia. Resultados: Cento e quarenta e nove (149) pessoas responderam ao questionário (49,6% do sexo feminino e idade média de 37 anos - IC=21-59 anos). Quanto às especialidades temos 90 (60,4%) de profissionais de saúde em geral (enfermeiros, técnicos de enfermagem, dentistas), seis (4,0%) de médicos e 53 (35,6%) de outras profissões técnicas (auxiliares de secretaria, motoristas). No geral, a maioria das pessoas tem um conhecimento adequado sobre epilepsia. Porém, algumas crenças ainda estão presentes. No que se refere à percepção, idéias erradas apareceram, como epilepsia é uma doença contagiosa, pessoas com epilepsia não podem praticar esportes ou trabalhar. Além disso, dúvidas referentes à gestação e ao tratamento da epilepsia também foram observadas. Com relação às atitudes durante uma crise epiléptica, apareceram: colocar algum objeto na boca do paciente, restringir movimentos do paciente ou dar álcool para a pessoa cheirar para poder interromper a crise. Conclusão: Neste contexto, são necessários programas de treinamento continuado para profissionais da área da saúde para melhorar a percepção e as atitudes perante esta condição, tirando assim a epilepsia das sombras.

Unitermos: cuidado à epilepsia, serviço médico, profissionais da saúde, educação, atenção básica à saúde.

<sup>\*</sup> Department of Neurology - Faculty of Medical Sciences/State University of Campinas (UNICAMP).

<sup>\*\*</sup> ASPE – Assistência à Saúde de Pacientes com Epilepsia.

<sup>\*\*\*</sup> SAMU-192 – Campinas, SP.

Received Aug. 05, 2009; accepted Sept. 01, 2009.

# INTRODUCTION

Epilepsy is very prevalent in our society, but unfortunately lack of knowledge is still very common, contributing to psycho-social difficulties to people with epilepsy.<sup>1.6</sup> This is not exclusive from Brazil, some countries all over the world as England,<sup>7.9</sup> United States,<sup>10</sup> Netherlands<sup>11</sup> experience the same situation. The myth ranging from patient swallows his/her tongue during a seizure to evil spirit possession is still a common place. All together adding inadequate attitudes during an ictal event bring danger to the patient.

In Brazil, we have the SAMU-192 (Serviço de Atendimento Móvel de Urgência), which is an emergency mobile unit service part of our public health system. This emergency medical service provides 24 hours support, dispatch mobile units and transfer to reference center in the necessary cases. In a period of six months in 2007 (July-December), SAMU-192 got on average 200 phone calls daily; 10 of those (4.7%) were epilepsy cases.

In this context, the purpose of this paper was to assess the epilepsy' perception and attitude by professionals of emergency medical service in the city of Campinas, an urban city with over one million people located in southeastern Brazil.

# MATERIAL AND METHODS

### Subjects

This survey was carried out with professionals of SAMU-192, who participated on the VII Stroke Workshop of Campinas in November 2007. This event was sponsored by Boerhinger Ingelheim and was dedicated to all professionals of SAMU-192 of Campinas. A total of 205 professionals attended the meeting.

# Instrument

We performed a survey using a self report anonymous questionnaire. The heading has demographic data with age, sex, and profession. This questionnaire had 22 questions in which subjects mark true or false or don't know. The first question had emphasis in perception and general knowledge about epilepsy and the second one highlighted the attitudes towards an epileptic seizure, as follows.

1. Mark "T - True" or "F - False" or "DNK - Do not know" in the following questions:

a)	Epilepsy is a contagious disease	(	)		
b)	People with epilepsy can not do physical exercise	(	)		
c)	Epilepsy is a neurological condition				
d)	During pregnancy, women with epilepsy should				
	interrupt the anti-epileptic drugs	(	)		

e)	Epilepsy is a spiritual disease	(	)
f)	The saliva can be contagious	(	)
g)	Epilepsy is a God punishment	(	)
h)	Epilepsy is a treatable condition	(	)
i)	Women with epilepsy can breastfeed	(	)
j)	People with epilepsy can have normal children	(	)
k)	Epilepsy is an evil possession	(	)
1)	People with epilepsy can work	(	)
m)	Epilepsy is a sign of weakness	(	)

# 2. During an epileptic seizure – convulsion – what would you do? Mark "T – True" or "F – False" or "DNK – Do not know" in the following questions:

a)	Restrict movements	(	)	
b)	Place the head on one side	(	)	
c)	Give alcohol to smell	(	)	
d)	Put some object in the mouth to avoid swallow			
	the tongue	(	)	
e)	Take out dangerous objects	(	)	
f)	Spread vinegar or alcohol on patient's wrist	(	)	
g)	Loosen tie	(	)	
h)	Calm people around	(	)	
i)	After the seizure, explain to the patient that he			
	(she) had an epilepsy seizure	(	)	

The answers were categorized and grouped accordingly and the level of significance was set at p < 0.05.

### Procedure

We approached all the participants of the Workshop and ask them to participate in the survey. They were asked to answer anonymous and individually. The condition was the same and it took on average 10 minutes for them to answer.

### RESULTS

One hundred-forty nine (149) out of 205 (73%) professionals answered the questionnaire, 49% were women, average age of 37 years (range from 21 to 59 year). Ninety (60%) were health professionals (nurses, health auxiliary, dentists), six (4%) were physicians and 53 (36%) were other professions (secretary, driver). Table 1 provides the perception of epilepsy and Table 2 shows the attitudes towards an epileptic seizure.

## DISCUSSION

This study, cross-sectional prospective with a convenience sample of professionals of SAMU-192, pointed some interesting results. As observed, we have a very low number of physicians who answered the questionnaire, which limits our generalization, but we believe that the singularities of answers showed some aspects of perceptions and attitudes towards epilepsy.

### Table 1. Epilepsy's perception

	Physicians % (n); n=6				th professi % (n); n=9		Other professionals % (n); n=53		
	Т	F	DNK	Т	F	DNK	Т	F	DNK
Epilepsy is a contagious disease.	-	100 (6)	-	-	100 (90)	-	1.9 (1)	98.1 (52)	-
People with epilepsy can not do physical exercise.	-	100 (6)	-	16.7 (15)	80.0 (71)	2.2 (3)	13.5 (7)	84.6 (45)	1.9(1)
Epilepsy is a neurological condition.	100 (6)	-	-	96.6 (86)	3.4 (4)	-	94.2 (50)	5.8 (3)	-
During pregnancy, women with epilepsy should interrupt the anti-epileptic drugs.	-	83.3 (5)	16.7 (1)	7.8 (7)	75.6 (68)	16.7 (15)	9.6 (5)	69.2 (37)	21.2 (11)
Epilepsy is a spiritual disease.	-	100 (6)	-	-	100 (90)	-	-	94.2 (50)	5.8 (3)
The saliva can be contagious.	-	100 (6)	-	2.2 (2)	96.7 (87)	1.1 (1)	1.9 (1)	98.1 (52)	-
Epilepsy is a God punishment.	-	100 (6)	-	-	100 (90)	-	-	98.1 (52)	1.9(1)
Epilepsy is a treatable condition.	100 (6)	-	-	96.7 (87)	2.2 (2)	1.1 (1)	88.5 (47)	11.5 (6)	-
Women with epilepsy can breastfeed.	100 (6)	-	-	91.1 (82)	2.2 (2)	6.7 (6)	96.2 (51)	-	3.8 (2)
People with epilepsy can have normal children.	100 (6)	-	-	97.8 (88)	1.1 (1)	1.1 (1)	98.1 (52)	-	1.9(1)
Epilepsy is an evil possession.	-	100 (6)	-	-	100 (90)	-	-	94.2 (50)	5.8 (3)
People with epilepsy can work.	100 (6)		-	97.8 (88)	2.2 (2)	-	98.1 (52)	1.9(1)	-
Epilepsy is a sign of weakness.	-	100 (6)	-	1.1 (1)	98.9 (89)	-	-	100 (53)	-

T=True; F=False; DNK=Do not know.

Table 2. Attitudes towards an epileptic seizure (convulsion)

	Physicians % (n); n=6				th professio % (n); n=90		Other professionals % (n); n=53		
	Т	F	DNK	Т	F	DNK	Т	F	DNK
Restrict movements.	33.3 (2)	66.7 (4)	-	28.9 (26)	68.9 (62)	2.2 (2)	36.5 (19)	55.8 (30)	7.7 (4)
Place the head on one side.	83.3 (5)	16.7(1)	-	96.7 (87)	3.3 (3)	-	98.1 (52)	-	1.9(1)
Give alcohol to smell.	-	100 (6)	-	1.1(1)	97.8 (89)	1.1(1)	-	100 (53)	-
Put some object in the mouth.	-	100 (6)	-	10.0 (9)	85.6 (77)	4.4 (4)	13.5 (7)	86.5 (46)	-
Take out dangerous objects.	100 (6)	-	-	97.8 (88)	1.1 (1)	1.1(1)	94.2 (50)	5.8 (3)	-
Spread vinegar or alcohol on patient's wrist.	-	100 (6)	-	-	96.7 (87)	3.3 (3)	-	98.1 (52)	1.9(1)
Loosen tie.	100 (6)	-	-	94.4 (85)	4.4 (4)	1.1(1)	94.2 (50)	3.8 (2)	1.9(1)
Calm people around.	100 (6)	-	-	96.7 (87)	1.1 (1)	2.2 (2)	94.2 (50)	5.8 (3)	-
After the seizure, explain to the patient that he (she) had an epilepsy seizure.	100 (6)	-	-	95.6 (86)	4.4 (4)	-	96.2 (51)	1.9 (1)	1.9 (1)

T=True; F=False; DNK=Do not know.

In overall, a great majority of the subjects had an appropriate knowledge regarding epilepsy. Nevertheless, some beliefs are still present.

In relation to epilepsy' perception, some wrong ideas appeared, fortunately in low percentage as epilepsy is a contagious disease, people with epilepsy can not practice physical exercise or work.<sup>2,12,13</sup> Also, the doubts regarding pregnancy and treatment of epilepsy were observed and show us the importance of continuous information and adequate knowledge about this condition.<sup>14,15</sup>

Regarding attitudes during an epileptic seizure, some inadequate attitudes appeared. The most striking is to put something in patient's mouth, which is often motivated by the fear of the patient swallows his/her tongue.<sup>1,12,16</sup> Some people still restrict the patients' movements or give something strong to smell (alcohol or vinegar) in order to stop the seizure. Needless to say the danger that such procedure can cause to the patients. In addition our previous study<sup>17</sup> showed that wrong attitude contribute to increase prejudice towards patients with epilepsy. The professionals allied to medicine are regarded as reliable source of information by many in our society. Thus they are required to know the basics of epilepsy especially how to proceed during a seizure as they are in the front line of urgency/emergency health care delivery.

In conclusion, in order to improve the perception and attitudes regarding epilepsy it is necessary continuous education programs to the professionals allied to medicine. These programs open the new perspective of epilepsy in our society, bringing epilepsy out of the shadows.

### REFERENCES

- 1. Fernandes PT, Li LM. Estigma na Epilepsia Departamento de Neurologia FCM/UNICAMP; 2005.
- Fernandes PT, Salgado PC, Noronha ALA, de Boer HM, Prilipko L, Sander JW, et al. Epilepsy stigma perception in an urban area of a limited resource country. Epilepsy Behav 2007;11(1):25-32.
- Guerreiro CA, Guerreiro MM, Cendes F, Lopes-Cendes I. Considerações gerais. In: Lemos Editorial. Epilepsia. 3rd ed. São Paulo; 2000. p. 1-10.
- Li LM, Sander JW. [National demonstration project on epilepsy in Brazil]. Arq Neuropsiquiatr 2003 Mar;61(1):153-6.

- Marchetti RL, de Castro AP, Daltio CS, Cremonese E, Ramos JM, Neto JG. Attitudes of Brazilian psychiatrists toward people with epilepsy. Epilepsy Behav 2004 Dec;5(6):999-1004.
- 6. Marchetti RL. [Epilepsy in the shadow of Brazilian psychiatry]. Rev Bras Psiquiatr 2004 Mar;26(1):67-8.
- Jacoby A, Chadwick D. Psychosocial problems in epilepsy. BMJ 1992 July;305(6845):117.
- Jacoby A, Gorry J, Gamble C, Baker GA. Public knowledge, private grief: a study of public attitudes to epilepsy in the United Kingdom and implications for stigma. Epilepsia 2004 Nov;45(11): 1405-15.
- 9. Baker G. The Psychosocial Burden of Epilepsy. Epilepsia 2002;43 (Suppl. 6):26-30.
- Austin JK, Shafer PO, Deering JB. Epilepsy familiarity, knowledge, and perceptions of stigma: report from a survey of adolescents in the general population. Epilepsy Behav 2002 Aug;3(4): 368-75.
- Suurmeijer TP, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. Epilepsia 2001 Sept;42(9):1160-8.
- Fernandes PT, Li LM. Percepção de estigma na epilepsia. Journal of Epilepsy and Clinical Neurophysiology 2006;12(4):207-18.

- Jacoby A. Impact of epilepsy on employment status: findings from a UK study of people with well-controlled epilepsy. Epilepsy Res 1995 June;21(2):125-32.
- 14. 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.
- Noronha AL, Fernandes PT, Andrade MGG, Santiago SM, Sander JW, Li LM. Training medical students to improve the management of people with epilepsy. Arq Neuropsiquiatr 2007;65 (Supl 1):23-7.
- Fernandes PT, Salgado PC, Noronha ALA, Barbosa FD, Souza EA, Li LM. Stigma Scale of Epilepsy: conceptual issues. Journal of Epilepsy and Clinical Neurophysiology 2004;10(4):213-8.
- Reno BA, Fernandes PT, Bell GS, Sander JW, Li LM. Stigma and attitudes on epilepsy: a study with secondary school students. Arq Neuropsiquiatr 2007;65(Supl 1):49-54.

#### Correspondence address:

Li Li Min Department of Neurology – FCM/UNICAMP Cx. Postal 6111 CEP 13083-970, Campinas, SP, Brazil Tel/Fax: (55-19) 3521-7292 E-mail: limin@fcm.unicamp.br