Arq Neuropsiquiatr 2007;65(Supl 1):35-42

STIGMA SCALE OF EPILEPSY

Validation process

Paula T. Fernandes[1,2], MSc, PhD; Priscila C.B. Salgado[1,2], MSc;
Ana L.A. Noronha[1,2], MD, PhD; Josemir W. Sander[3,4], MD, PhD, FRCP; Li M. Li[1,2], MD, PhD

ABSTRACT - *Purpose:* To validate a Stigma Scale of Epilepsy (SSE). *Methods:* The SSE was completed by 40 adult with epilepsy attending an Outpatient Epilepsy Clinic at the University Hospital of UNICAMP, and by 40 people from the community. People were interviewed on an individual basis; a psychologist read the questions to the subjects who wrote the answers in a sheet. The procedure was the same for all the subjects and completion took around ten minutes. *Results:* The SSE has 24 items. The internal consistency of the SSE showed α Cronbach's coefficient 0.88 for the patients with epilepsy and 0.81 for the community. The overall mean scores of the Stigma Scale of Epilepsy formula were: 46 (SD=18.22) for patients and 49 (SD=13.25) for the community where a score of 0 would suggest no stigma, and 100 maximum stigma. *Discussion:* The SSE has satisfactory content validity and high internal consistency. It allows the quantification of the perception of stigma by patients and people from community; this can then be used for interventional studies, such as mass media campaign in minimizing the negative facets of stigma.

KEY WORDS: stigma, epilepsy, instrument development, quality of life, validation, stigma scale.

Escala de estigma na epilepsia: processo de validação

RESUMO - *Objetivo:* Validar a Escala de Estigma na Epilepsia (EEE). *Método:* A EEE foi aplicada em 40 pacientes adultos com o diagnóstico de Epilepsia do Ambulatório de Epilepsia do HC/Unicamp e em 40 pessoas da comunidade em geral. Os sujeitos foram entrevistados individualmente pelas psicólogas, que foram lendo as questões e anotando as respostas na escala. As condições de aplicação foram as mesmas e a aplicação durou cerca de 10 minutos. *Resultados:* A EEE possui 24 itens. A consistência interna da EEE mostrou α de Cronbach, de 0,88 para os pacientes com epilepsia e 0,81 para a comunidade. As médias do valor geral de estigma obtido com a fórmula da EEE foram: 46 (DP=18,22) para os pacientes e 49 (DP=13,25) para a comunidade. *Discussão:* A EEE possui uma satisfatória validade e alta consistência interna. Isso permite uma quantificação da percepção de estigma da epilepsia na comunidade em geral, que pode ser utilizada para estudos interventivos, como campanhas na mídia, para minimizar as facetas negativas do estigma na sociedade.

PALAVRAS-CHAVE: estigma, epilepsia, criação de instrumento, qualidade de vida, validação, escala de estigma.

Epilepsy is a common neurological condition, frequently associated with psycho-social difficulties[1-3]. Prejudice and discrimination are often worse than the seizures themselves[4,5] in terms of impact on daily life of people with epilepsy. According to some studies carried out in Europe[3,5-7] and North America[8-11] the stigma of epilepsy is considered one of the most important negative influences on the quality of life of people with epilepsy.

Epilepsy is said to be a stigmatizing condition as people do not conform to social norms as a result of unpredictable seizures, and consequently society dreads dealing with someone who is having an epileptic seizure[12]. From the patient's view, the diagnosis of epilepsy triggers a change in perception, bringing on fears of being different and anxiety about the future in the community, with apprehension about getting a job or starting a family[13]. Perception is often negative, which may impair the patient's quality of life and reinforces the stigma[13].

It is clear that epilepsy affects behaviour and quality of life not only for the person who has epilepsy,

---

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

Dr. Li Li Min - Department of Neurology / UNICAMP - Cx. Postal 6111 - 13083-970 Campinas SP - Brazil. E-mail: limin@fcm.unicamp.br or li@aspebrasil.org; Site: http://www.aspebrasil.org

but also for the entire family[3,6,14,15]. This fact is well known, but paradoxically this facet of epilepsy is rarely studied, especially in developing countries[16], where the burden of epilepsy stigma is probably very high.

Stigma is a term frequently used nowadays, but it is still difficult to conceptualize and measure it. Studies[17-20] portray stigma in somewhat different perspectives, and the results are derived from qualitative assessments. We wish to highlight the importance of the study of stigma of epilepsy, emphasizing that a specific quantitative instrument for its evaluation should be created[16].

The process of creation of a scale involves several methodological steps[21]. In order to elaborate the Stigma Scale of Epilepsy (SSE), firstly we had to review the definition of the attribute, delimitation of the population and characterization of the item type[21]. Because of the lack of instruments to evaluate epilepsy stigma locally, our first instrument was an exploratory and open questionnaire with general questions to patients and lay people from the local community. To create these questions, we reviewed the literature and our clinical experience in epilepsy. A panel of three specialists not involved in the project evaluated the questions, and afterwards the most appropriate items were chosen. We interviewed 20 patients and 20 lay people using an open questionnaire on the global perception of epilepsy and its impact; details are published elsewhere[22]. Briefly, the overall result showed that there is a poor knowledge of epilepsy among those interviewed, although most of them have received information from their doctors. In regard to the social aspects, most of them referred to difficulties in work and school environments and also in establishing relationships. The main feelings highlighted by patients and relatives about epilepsy were sadness, dependence, inferiority, insecurity, fear and pity.

Based on the results of this first questionnaire[22], we reviewed the questions and answers to produce a closed questionnaire[23]. A multiple-choice questionnaire was created and completed by 12 patients and 32 lay people. Based on those answers we selected the most common (50% cut-off) items for the final version of SSE.

In order to overcome the lack of a gold-standard for internal correlation, we proposed a comparison of how people perceive other chronic conditions[24], which carry different weights of stigma. In this context, we assessed whether there were differences in stigma perception towards epilepsy and two other prevalent and chronic conditions, but with distinct degree of stigma, AIDS and diabetes. The result from 145 lay people and 86 patients and relatives showed that AIDS had the highest level of prejudice and diabetes the lowest, and epilepsy was in the middle, closer to AIDS[24].

The objective of this paper is to present the validation of the Stigma Scale of Epilepsy (SSE). This is phase III of the Demonstration Project on Epilepsy in Brazil, part of WHO/ILAE/IBE Global Campaing Against Epilepsy, executed by ASPE, Assistência à Saúde de Pacientes com Epilepsia[16].

METHOD

Stigma scale of epilepsy - content and scoring – After the analysis of results obtained in the previous phases described and published elsewhere[22-25], the Stigma Scale of Epilepsy (SSE)[25] was finalized. It now contains five questions with twenty-four items, each with a four-point scale: the individuals were asked to indicate the most appropriate answer for that item, marking the number corresponding to the category (1 not at all, 2=a little, 3=a lot, 4=totally).

Comparative factor in the validation process – For validation purposes, it was necessary to compare to other questions related to stigma. As described above, we used questions to compare the perception of epilepsy with that of diabetes and AIDS. These questions are:

– What score would you rate for the prejudice that the general population has towards epilepsy (0=no prejudice, 10=maximum prejudice)?
– What score would you rate for the prejudice that the general population has towards AIDS (0=no prejudice, 10=maximum prejudice)?
– What score would you rate for the prejudice that the general population has towards diabetes (0=no prejudice, 10=maximum prejudice)?

A further question was asked to give an idea of the distribution of the stigma scores and the perception of stigma in society:

– Do you believe that people with epilepsy are stigmatized or rejected by society? (Yes or No).

In addition, another scale was used in the study - QQV-65, *Questionário de Qualidade de Vida* – with 65 questions[26], that evaluates the quality of life of people with epilepsy, through the following domains: perception of health, physical limitations, social aspects, satisfaction, perception of control, affective-emotional aspects, self-image, cognitive aspects, work and leisure. This scale was completed only by patients to compare two important aspects in the daily life of people with epilepsy: stigma and quality of life. Our prior hypothesis was that there would be a negative correlation between these aspects.

Sampling and questionnaire administration – The subjects were divided in two groups:

1. Patients from the Epilepsy Outpatient Clinic of the Hospital of State University of Campinas (UNICAMP), SP, Brazil.

2. People in the community.

All subjects gave informed consent. The study was approved by the Ethics Committee of UNICAMP (number 064/2002).

Two psychologists (PTF, PCBS) interviewed people on an individual basis; the question was read by the psychologist and the subject then wrote down the answers. The form was the same for all the subjects.

Plan of analysis – The following statistical tests were used for scale analysis [27-29]:

- Descriptive statistics were used for continuous variables and frequency for categorical variables.
- Cronbach's α coefficient for reliability and internal consistency was used for validation and verification of the consistency of the instrument. This coefficient is used to verify the homogeneity or accuracy of instrument items. The accuracy should not be lower than 0.80 if the scale is widely used, although values above 0.60 indicate consistency[27].
- Pearson correlation coefficient and Mann-Whitney U test was applied for analysis of comparative questions with variables of interest.
- Spearman correlation coefficient was used to correlate the score of stigma in epilepsy with the QQV-65 score. The significance level used was 5% (p-value < 0.05).

The items scores from the questionnaire were summed and the score is linearly transformed onto a 0-100 scale, with 0 indicating no stigma and 100 indicating highest level of stigma of epilepsy.

RESULTS

We interviewed 80 subjects (40 patients and 40 people in the community). The main characteristics of the population studied are shown in Table 1.

Descriptive analyses

Comparative questions – In the group of patients, the median prejudice score was 7 for epilepsy, 8 for

Table 1. Characteristics of the subjects (80 people=40 patients and 40 people in the community).

Characteristics	Community n=40 (%)	Patients n=40 (%)
Mean age	35	39
Gender		
Men	13 (32.5%)	17 (42.5%)
Women	27 (67.5%)	23 (57.5%)
Religion		
Without religion	7 (17.5%)	2 (5%)
Catholic	24 (60%)	22 (55%)
Evangelical	6 (15%)	14 (35%)
Spiritist	2 (5%)	1 (2.5%)
Others	1 (2.5%)	1 (2.5%)
School level		
Illiterate/incomplete elementary school	7 (17.5%)	6 (15%)
Complete elementary school/incomplete high school	24 (60%)	16 (40%)
Complete high school/incomplete college	6 (15%)	4 (10%)
Complete college/incomplete university degree	2 (5%)	12 (30%)
University degree	1 (2.5%)	2 (5%)

Epilepsy' characteristics of patients

Characteristics	Patients n=40 (%)
Mean age of seizure onset	13.69 (0-55)
Mean age of epilepsy diagnosis	17.87 (1-55)
Medical treatment	
Yes	40 (100%)
No	0
Seizure type	
Partial seizure	10 (27.5%)
Partial seizure with a secondary generalization	24 (57.5%)
Generalized seizure	6 (15%)

Table 2. Stigma scale of epilepsy questions and the results from 40 control subjects and 40 people with epilepsy.

	Community n=40 (%)				Patients n=40 (%)			
	Not at all	A little	A lot	Totally	Not at all	A little	A lot	Totally
Do you think that people with epilepsy feel able to control their own epilepsy?								
	24 (60.0)	9 (22.5)	7 (17.5)	0	17 (42.5)	11 (27.5)	10 (25.0)	2 (5.0)
How would you feel when you see an epileptic seizure?								
Scared	12 (30.0)	4 (10.0)	19 (47.5)	5 (12.5)	13 (32.5)	9 (22.5)	12 (30.0)	6 (15.0)
Fear	26 (65.0)	6 (15.0)	14 (35.0)	6 (15.0)	23 (57.5)	5 (12.5)	10 (25.0)	9 (22.5)
Sadness	9 (22.5)	8 (20.0)	17 (42.5)	6 (15.0)	7 (17.5)	10 (25.0)	15 (37.5)	8 (20.0)
Pity	15 (37.5)	5 (12.5)	14 (35.0)	6 (15.0)	9 (22.5)	12 (30.0)	10 (25.0)	9 (22.5)
Which difficulties do you think people with epilepsy have in their daily lives?								
Relationships	18 (45.0)	8 (20.0)	12 (30.0)	2 (5.0)	15 (37.5)	10 (25.0)	13 (32.5)	2 (5.0)
Work	5 (12.5)	4 (10.0)	24 (60.0)	7 (17.5)	6 (15.0)	9 (22.5)	15 (37.5)	10 (25.0)
School	7 (17.5)	9 (22.5)	18 (45.0)	6 (15.0)	7 (12.5)	13 (32.5)	15 (37.5)	5 (12.5)
Friendships	10 (25.0)	9 (22.5)	15 (37.5)	6 (15.0)	13 (32.5)	11 (27.5)	11 (27.5)	6 (12.5)
Sexual	9 (22.5)	14 (35.0)	14 (35.0)	3 (7.5)	17 (42.5)	6 (15.0)	12 (30.0)	5 (12.5)
Emotional	4 (10.0)	5 (12.5)	24 (60.0)	7 (17.5)	6 (10.0)	10 (25.0)	18 (45.0)	6 (15.0)
Prejudice	4 (10.0)	5 (12.5)	18 (45.0)	13 (32.5)	12 (30.0)	12 (30.0)	4 (28.0)	12 (30.0)
How do you think that people with epilepsy feel?								
Worried	4 (10.0)	10 (25.0)	16 (40.0)	10 (25.0)	7 (17.5)	6 (15.0)	14 (35.0)	13 (32.5)
Dependent	5 (12.5)	10 (25.0)	16 (40.0)	9 (22.5)	11 (27.5)	8 (20.0)	10 (25.0)	11 (27.5)
Incapable	21 (52.5)	8 (20.0)	8 (20.0)	3 (7.5)	23 (57.5)	8 (20.0)	3 (7.5)	6 (15.0)
Fearful	7 (17.5)	10 (25.0)	20 (50.0)	3 (7.5)	12 (30.0)	11 (27.5)	13 (32.5)	4 (10.0)
Depressed	6 (15.0)	12 (30.0)	19 (47.5)	3 (7.5)	10 (25.0)	10 (25.0)	9 (22.5)	10 (25.0)
Ashamed	9 (22.5)	9 (22.5)	16 (40.0)	6 (15.0)	15 (37.5)	9 (22.5)	9 (22.5)	7 (17.5)
The same as those without epilepsy	24 (60.0)	8 (20.0)	7 (17.5)	1 (2.5)	20 (50.0)	7 (17.5)	9 (22.5)	3 (7.5)
In your opinion, the prejudice in epilepsy will be related to?								
Relationships	3 (12.5)	12 (30.0)	21 (52.5)	4 (10.0)	8 (20.0)	15 (37.5)	14 (35.0)	3 (7.5)
Marriage	21 (52.5)	7 (17.5)	10 (25.0)	2 (5.0)	15 (37.5)	9 (22.5)	12 (30.0)	4 (10.0)
Work	5 (12.5)	9 (22.5)	19 (47.5)	7 (17.5)	9 (22.5)	9 (22.5)	14 (35.0)	8 (20.0)
School	7 (17.5)	10 (25.0)	18 (45.0)	5 (12.0)	10 (25.0)	7 (17.5)	16 (40.0)	7 (17.5)
Family	19 (47.5)	13 (32.5)	6 (15.0)	2 (5.0)	16 (40.0)	15 (37.5)	6 (15.0)	3 (7.5)

AIDS and 5 for diabetes. Non-parametric analysis showed a difference among the three groups (Friedman[2]=35, p<0.001). For the community group, the median prejudice score was 7 for epilepsy, 8 for AIDS and 2 for diabetes. Non-parametric analysis showed difference among the three groups (Friedman[2]=67, p<0.001). In both situations, Wilcoxon paired analysis corrected for multiple comparison showed significant difference among the three groups (AIDS> epilepsy>diabetes). The question "Do you think people with epilepsy are stigmatized or rejected by society?" showed that 72.5% of the community and 65.0% of the patients believed that people with epilepsy are stigmatized or rejected by society.

Table 2 shows the subjects' answers using the scale from 1 to 4 (range from not at all to totally), which were then used to calculate a SSE general score.

The mean and standard deviation (SD) of the total stigma scores obtained with the Stigma Scale of Epilepsy formula were: 46, SD=18.22 for patients and 49, SD=13.25 for community (see score instructions).

Descriptive statistics and scaling properties

Data quality – All the items of the questionnaire were answered. The mean time for completion of the scale was ten minutes. After completing the scale, on direct questioning the subjects stated that they did not have problems understanding the questions. Only two items had inverted scores (see score instructions).

Table 3. Pearson's correlation with comparative questions and the SSE score.

Comparative questions											
Epilepsy				AIDS				Diabetes			
Patients		Community		Patients		Community		Patients		Community	
R	P	R	P	R	P	R	P	R	P	R	P
0.3018	0.0655	0.3353	0.0344	0.0711	0.6713	0.0997	0.5402	0.0119	0.9443	0.0463	0.7764

R, Pearson's correlation coefficient; P, p-value. The scores rated for the prejudice that the general population has towards epilepsy, AIDS and diabetes (0=no prejudice, 10=maximum prejudice) when correlated for SSE score showed in overall a significant correlation only with epilepsy but not with AIDS or diabetes.

Table 4. SSE score correlated with the seven domains of quality of life questionnaire (QQV-65).

Domains of quality of life (QQV-65) in comparison to SSE score		
	R	p
Health	–0.59942	<.0001
Physical	0.39957	0.0106
Social	–0.41402	0.0079
Emotional	–0.52575	0.0005
Control	–0.32310	0.0420
Concept	–0.49052	0.0013
Cognition	–0.37323	0.0177
Total	–0.52245	0.0005

R, Spearman's correlation coefficient; P, p-value; SSE, showed a negative linear correlation with the domains of quality of life.

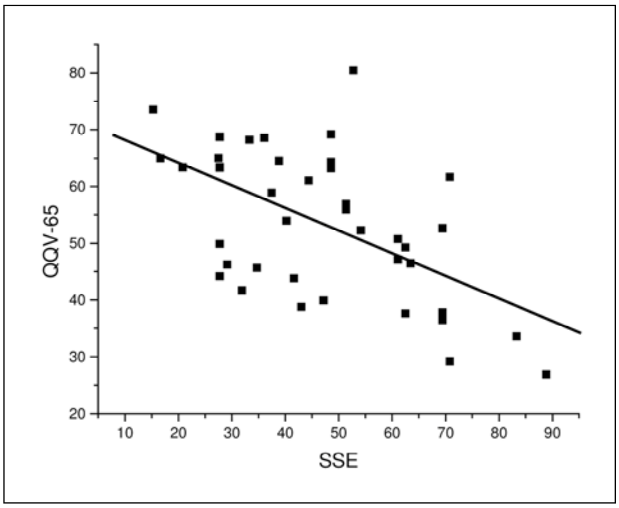


Fig 1. Comparison between stigma score (SSE) and quality of life (QQV-65). There is a significant negative correlation between the SSE score (x-axis) and quality of life (y-axis).

Reliability and validity – Reliability and validity evaluation: the internal consistency of the SSE for the score showed a general α Cronbach's coefficient was 0.88 for the patients with epilepsy and 0.81 for people in the community.

Comparative analysis – Table 3 shows Pearson Correlation Coefficients between SSE scores and the results of the questions "What score would you rate for the prejudice that the general population has towards people with Epilepsy, AIDS and Diabetes (0=no prejudice, 10=maximum prejudice)?".

Regarding the comparative question "Do you believe that people with epilepsy are stigmatized or rejected by society? (yes or no)", the median SSE score of patients that believe that people with epilepsy are stigmatized or rejected is 53, which is higher than the median SSE scores (38) of patients who don't believe it (Mann Whitney U test, p=0.01). Similarly, the median SSE score of people from the community who believe that people with epilepsy are stigmatized or rejected is 53, which is higher than the median SSE scores (36) of people who don't believe it (Mann Whitney U test, p=0.006).

The Quality of Life and Stigma are also correlated. Table 4 shows Spearman Correlation Coefficients of the SSE score in comparison with the QQV-65 instrument. Figure 1 shows the relation between score of Stigma Scale of Epilepsy and score of QQV-65.

DISCUSSION

SSE is one of the first instruments that allows quantification of stigma in epilepsy expressed as a scale. The questions of SSE have a satisfactory content validity and high internal consistence. It complies with the main requirements of a validation process[21], offering reliable measurements of stigma in epilepsy.

The choice of any evaluation scale is dependent on it being a measuring instrument, so that the answers can be ordered, to produce a numerical correlation[21]. Numerical scales are easy to analyze, allowing assessment of high numbers of subjects in an objective manner[21].

The process of validation of the SSE followed standards recommended for the preparation of scales[30-32], which involved two components: one conceptual and another empirical. The conceptual component is the assessment of the researcher of whether the instrument actually measures what it should measure. It is a subjective evaluation, with statistical methods. The operational validation involves an analysis of statistical methods, usually by comparing with gold-standard criteria, if available.

The results of the comparative questions replicated our previous finding[24], that there exists a difference in the stigma perception of chronic diseases such as epilepsy, AIDS and diabetes. AIDS had the highest level of stigma and diabetes, the lowest. Epilepsy was in the intermediate position but close to AIDS. The stigma measured by SSE appeared to be specific for epilepsy in the analysis of correlation with these questions. Furthermore, the results of a comparative instrument, QQV-65, completed by patients with epilepsy in relation with SSE also showed significant negative correlations to QQV-65, and showing that the higher the stigma score, the lower is the quality of life.

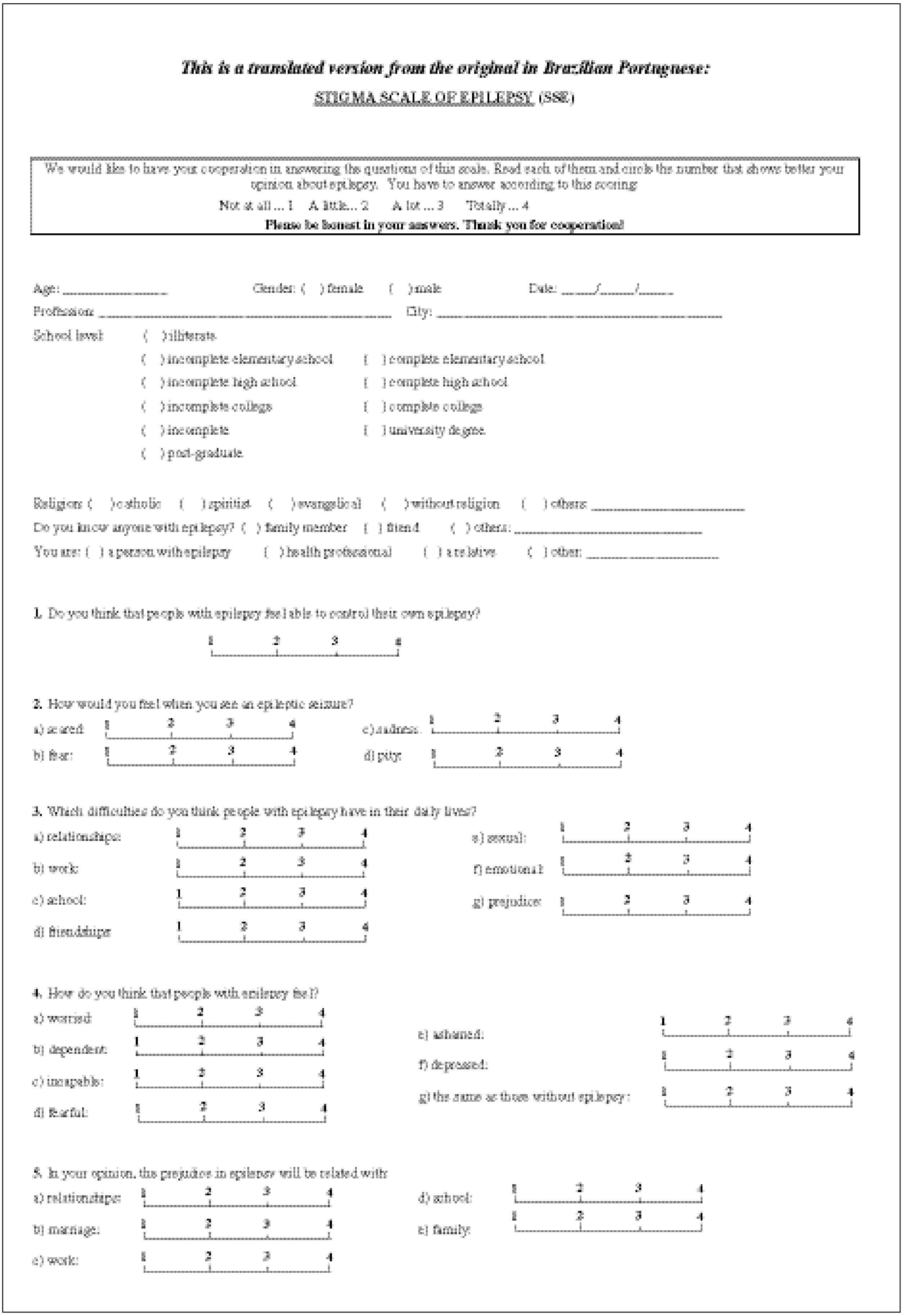
We believe that the reactions of patients and family members faced with epilepsy, as well as emotional and individual aspects of each person, reinforce inappropriate discriminatory behaviors[33-36]. Negative attitudes on the part of family and friends, in addition to difficulties in interpersonal relationships, are factors that perpetuate stigma in society[33]. The areas most affected by epilepsy observed in this study relate to difficulties at work, at school and in social interaction, activity restriction and negative feelings by patients.

In summary, we believe that the SSE is ready to be used and opens new prospects in the study of stigma in epilepsy as it allows objective quantification that can be used to assess intervention campaigns and cross cultural evaluation on this subject. The SSE can be used to provide quantitative data of the magnitude of the stigma perception of epilepsy in our society.

Acknowledgments – For the validation process, we would like to thank Priscila Yuriko Yassunaga and Helymar da Costa Machado for statistical support. We especially thank the subjects involved in this study for their cooperation.

REFERENCES

1. Jacoby A. Stigma, epilepsy and quality of life. Epilepsy Behav 2002;3:10-20.
2. MacLeod JS, Austin JK. Stigma in the lives of adolescents with epilepsy: a review of the literature. Epilepsy Behav 2003;4:112-117.
3. Baker G. The psychosocial burden of epilepsy. Epilepsia 2002;43:26-30.
4. Suurmeijer TP, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. Epilepsia 2001;42:1160-1168.
5. Fisher RS, Vickrey BG, Gibson P, et al. The impact of epilepsy from the patient's perspective I. Descriptions and subjective perceptions. Epilepsy Res 2000;41:39-51.
6. Jacoby A. Epilepsy and the quality of everyday life: findings from a study of people with well-controlled epilepsy. Soc Sci Med 1992;34:657-666.
7. Vickrey BG, Hays RD, Graber J, Rausch R, Engel Jr J., Brook RH. A health-related quality of life instrument for patients evaluated for epilepsy surgery. Med Care 1992;30:299-319.
8. Devinsky O, Vickrey BG, Cramer J, et al. Development of the quality of life in epilepsy inventory. Epilepsia 1995;36:1089-1104.
9. Austin JK, Dunn DW, Huster GA, Rose DF. Development of scales to measure psychosocial care needs of children with seizures and their parents. J Neurosci Nurs 1998;30:155-160.
10. 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;3:368-375.
11. DiIorio C, Osborne SP, Letz R, Henry T, Schomer DL, Yeager K. The association of stigma with self-management and perceptions of health care among adults with epilepsy. Epilepsy Behav 2003;4:259-267.
12. Goffman E. Stigma: notes on the management of spoiled identity. New York: Touchstone, 1963.
13. Scambler G, Hopkins A. Generating a model of epileptic stigma: the role of qualitative analysis. Soc Sci Med 1990;30:1187-1194.
14. McLin WM, de Boer HM. Public perceptions about epilepsy. Epilepsia 1995;36:957-959.
15. Collings JA. Psychosocial well-being and epilepsy: an empirical study. Epilepsia 1990;31:418-426.
16. Li LM, Sander JW. National demonstration project on epilepsy in Brazil. Arq Neuropsiquiatr 2003;61:153-156.
17. Baker GA, Jacoby A, Buck D, Stalgis C, Monnet D. Quality of life of people with epilepsy: a European study. Epilepsia 1997;38:353-362.
18. 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;45:1405-1145.
19. Herodes M, Oun A, Haldre S, Kaasik AE. Epilepsy in Estonia: a quality-of-life study. Epilepsia 2001;42:1061-1073.
20. Kleinman A, Wang WZ, Li SC, et al. The social course of epilepsy: chronic illness as social experience in interior China. Soc Sci Med 1995;40:1319-1330.
21. Bunchaft G, Cavas CST. Sob medida: um guia de elaboração de medidas do comportamento e suas aplicações. 2002.
22. 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.
23. Salgado PC, Fernandes PT, Noronha AL, Barbosa FD, Souza EA, Li LM. The second step in the construction of a stigma scale of epilepsy. Arq Neuropsiquiatr 2005;63:395-398.
24. Fernandes PT, Salgado PC, Noronha ALA, et al. Prejudice towards chronic diseases: comparison among AIDS, diabetes and epilepsy. Seizure 2007;in press doi: 10.1016/j.seizure.2007.01.008.
25. Fernandes PT, Li LM. Estigma na epilepsia. 1-207. 2005. Departamento de Neurologia - FCM/UNICAMP. PhD Thesis.
26. Souza EA. Questionário de qualidade de vida na epilepsia. Arq Neuropsiquiatr 2001;59:541-544.
27. Pagano M, Gauvreau K. Princípios de Bioestatística. São Paulo: 2004.
28. SAS System for Windows (Statistical Analysis System) 8.02. 2001. SAS Institute Inc, Cary, USA.
29. Hatcher L. A step-by-step approach to using the SAS system for factor analysis and structural equation modeling. USA: 1994.
30. Menezes PR, Nascimento AF. Validade e confiabilidade das escalas de avaliação em psiquiatria. In: Gorestein C, Andrade LHSG, Waldo A, eds. Escalas de avaliação clínica em psiquiatria e psicofarmacologia. São Paulo: Lemos Editorial, 2000:23-28.
31. Almeida Filho N, Santana VS, Mari JJ. Princípios de epidemiologia para profissionais de saúde mental. Brasília, 1989.
32. Morley S, Snaith P. Principles of psychological assessment. In Freeman C, Tyrer P (Eds). Research methods in psychiatry. London: Gaskell, 1989.
33. Ablon J. The nature of stigma and medical conditions. Epilepsy Behav 2002;3:2-9.
34. Baker GA, Brooks J, Buck D, Jacoby A. The stigma of epilepsy: a European perspective. Epilepsia 2000;41:98-104.
35. Schneider JW, Conrad P. Having epilepsy: the experience and control of illness. Philadelphia: Temple University Press, 1983.
36. Ryan R, Kempner K, Emlen AC. The stigma of epilepsy as a self-concept. Epilepsia 1980;21:433-444.



This is a translated version from the original in Brazilian Portuguese:

STIGMA SCALE OF EPILEPSY (SSE)

We would like to have your cooperation in answering the questions of this scale. Read each of them and circle the number that shows better your opinion about epilepsy. You have to answer according to this scoring:

Not at all ... 1 A little... 2 A lot ... 3 Totally ... 4

Please be honest in your answers. Thank you for cooperation!

Age: ________________ Gender: ( ) female ( ) male Date: _____/_____/_____

Profession: ______________________________ City: ______________________________

School level: ( ) illiterate

( ) incomplete elementary school ( ) complete elementary school

( ) incomplete high school ( ) complete high school

( ) incomplete college ( ) complete college

( ) incomplete ( ) university degree

( ) post-graduate

Religion: ( ) catholic ( ) spiritist ( ) evangelical ( ) without religion ( ) others: ____________________

Do you know anyone with epilepsy? ( ) family member ( ) friend ( ) others: ______________________

You are: ( ) a person with epilepsy ( ) health professional ( ) a relative ( ) other: __________________

1. Do you think that people with epilepsy feel able to control their own epilepsy?

1 2 3 4

2. How would you feel when you see an epileptic seizure?

a) scared: 1 2 3 4

b) fear: 1 2 3 4

c) sadness: 1 2 3 4

d) pity: 1 2 3 4

3. Which difficulties do you think people with epilepsy have in their daily lives?

a) relationships: 1 2 3 4

b) work: 1 2 3 4

c) school: 1 2 3 4

d) friendships: 1 2 3 4

e) sexual: 1 2 3 4

f) emotional: 1 2 3 4

g) prejudice: 1 2 3 4

4. How do you think that people with epilepsy feel?

a) worried: 1 2 3 4

b) dependent: 1 2 3 4

c) incapable: 1 2 3 4

d) fearful: 1 2 3 4

e) ashamed: 1 2 3 4

f) depressed: 1 2 3 4

g) the same as those without epilepsy: 1 2 3 4

5. In your opinion, the prejudice in epilepsy will be related with:

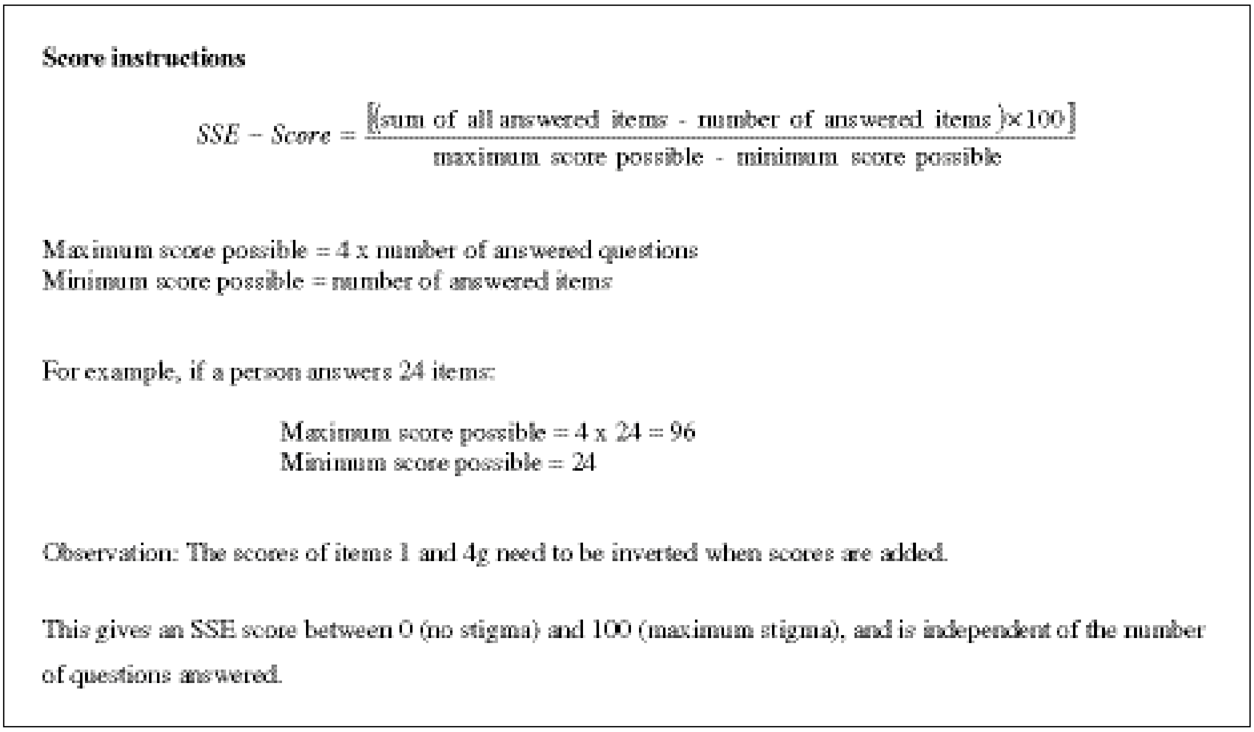
a) relationships: 1 2 3 4

b) marriage: 1 2 3 4

c) work: 1 2 3 4

d) school: 1 2 3 4

e) family: 1 2 3 4



Score instructions

$$SSE - Score = \frac{\left[(\text{sum of all answered items - number of answered items})\times 100\right]}{\text{maximum score possible - minimum score possible}}$$

Maximum score possible = 4 x number of answered questions
Minimum score possible = number of answered items

For example, if a person answers 24 items:

Maximum score possible = 4 x 24 = 96
Minimum score possible = 24

Observation: The scores of items 1 and 4g need to be inverted when scores are added.

This gives an SSE score between 0 (no stigma) and 100 (maximum stigma), and is independent of the number of questions answered.