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Epilepsy Perception Amongst Education Professionals

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ABSTRACT

Introduction: Epilepsy is a prevalent neurological disorder that may cause school failure due to several factors such as seizure severity, lack of information about the condition and stigma. This study aimed to evaluate the degree of perceived stigma and knowledge towards epilepsy among education professionals, and additionally, provide them correct information about epilepsy to reduce stigma through a training course. **Methods:** Social and demographic data, as well as the degree of stigma were obtained through the Stigma Scale of Epilepsy. To estimate the level of educational professionals' knowledge about epilepsy we used the Questionnaire about Epilepsy. Statistical analysis consisted of Pearson's or Spearman's correlation tests for numerical parametric or non-parametric variables were used to determine potential significant associations. A $p < 0.05$ was considered significant. **Results:** Two hundred and twenty-five education professionals were interviewed in three different cities in Southern Brazil. Approximately 65% of subjects would attempt to open the mouth of a student during a seizure and the stigma measured by Stigma Scale of Epilepsy before the course was 45.4±16.61. **Conclusion:** The data indicate that education professionals have partial knowledge about epilepsy and a short duration course would be able to improve it and reduce its stigma in this population.

Keywords: epilepsy education, stigma, education professionals, Questionnaire about Epilepsy, Stigma Scale of Epilepsy.

RESUMO

Percepção de epilepsia entre profissionais da educação

Introdução: A epilepsia é uma doença neurológica prevalente que pode causar fracasso escolar devido a fatores como severidade das crises, pouca informação sobre a doença e estigma. Este estudo teve como objetivo avaliar a percepção do estigma e conhecimento em epilepsia pelos profissionais de educação, fornecer informações corretas sobre epilepsia e reduzir o estigma através de um curso de curta duração. **Metodologia:** Os dados sociodemográficos e o grau de estigma foram obtidos através da Escala de Estigma em Epilepsia. O grau de conhecimento em epilepsia foi obtido através da adaptação do Questionário Sobre Epilepsia. O teste de correlação de Pearson ou Spearman foi utilizado para análise das variáveis numéricas contínuas paramétricas ou não-paramétricas. O valor de $p<0,05$ foi considerado significante. **Resultados:** Duzentos e vinte e cinco sujeitos foram entrevistados em três cidades do Sul do Brasil. Aproximadamente 65% deles abriria a boca do estudante durante uma crise e o grau do estigma avaliado com a Escala de Estigma em Epilepsia pré-curso foi de 45.4±16.61. **Conclusão:** Os dados indicam que os profissionais da educação têm um conhecimento pacial sobre epilepsia e que um curso de curta duração foi capaz de aumentar o conhecimento e reduzir o estigma na população estudada.

Palavras-chave: educação em epilepsia, profissionais da educação, Questionário sobre Epilepsia, Escala de Estigma em Epilepsia.

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INTRODUCTION

Most people with epilepsy have their first seizure before the age of 20, and it can affect their development. According to Souza and cols. (2002),[1] the diagnosis of epilepsy as a neurological condition, brings a series of burdens to the patient and his family, affecting their behavior and well-being. Being diagnosed with epilepsy activates a whole system of beliefs in personal and social levels that could potentially modify behavior towards oneself and society. Furthermore, it involves individual perceptions and expectations related to the life history of each affected person in different ways.

Epilepsy is the most common chronic neurological disorder in childhood, affecting approximately 3.6-5.3 children per 1000.[2] There is evidence of association between epilepsy and specific learning disabilities[3]. The difficulties presented by children with epilepsy may be related to epilepsy itself and also to variables involved with the schooling process such as: low expectations from parents and teachers about their success, rejection from teachers and schoolmates and low self-esteem.[4] Moreover, ignorance and stigma about the disease can also interfere with school attendance.[5] The starting point for any discussion related to stigma must be Goffman's[6] definition as "*an attribute that is deeply discrediting*".[7] Goffman asserted that an individual who is stigmatized possesses "*a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim his other attributes have on us*".[7]

It is crucial to provide knowledge about epilepsy and its care right after its diagnosis – regardless of the subject's age. Specific challenges include gaining control over such a chronic condition, often difficult to predict, and the stigma frequently associated. Therefore, education on epilepsy is extremely important. Children spend most time at school and the contribution of the education professionals in health education is essential. They are part of the social network of students with epilepsy, and, when well targeted, they will be more able to deal with adverse situations and unforeseen seizures at school environment. The educator is an important element in providing correct and non-biased information on several issues, including the health area.[8]

The aim of this study was to evaluate the level of knowledge and perception of the magnitude of stigma on epilepsy among basic education professionals before and after the attending to an educational course on epilepsy. This study will allow the development of more effective interventions regarding epilepsy education aiming to improve the psychosocial health of students with epilepsy. Although education professionals are able to confront these situations, there are few undergraduate programs that include courses on Inclusive Education, particularly on epilepsy, in Brazil.

METHODS

To estimate the level of educational professionals' knowledge about epilepsy we used the Questionnaire about Epilepsy (QAE), developed by *Associação Brasileira de Epilepsia* (ABE).[9,10] The questionnaire contains 35 statements concerning the following topics: A – Concepts and definition of epilepsy and its causes (10 items); B – Treatment and adverse effects of antiepileptic medication (10); C – Popular stigma about epilepsy (5); D – Activities of people with epilepsy (PWE) (5); E – First-aid during and after an epileptic seizure (5). Respondents were asked to indicate whether the statements were correct or wrong. Two more issues were added to the questionnaire, one on the topic "Activities of people with epilepsy" that is "People with epilepsy should attend special education" and another one on the topic "Treatment and medication adverse events" – "Epilepsy usually improves with religious or spiritual interventions". Additionally, it was added the option "I do not know" as a possible answer.

To determine the perception of stigma in epilepsy we used the Stigma Scale of Epilepsy (SSE).[11] This scale 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); with the highest score of 100 indicating maximum stigma.

The questionnaire and the SSE were presented to education professionals in phase 1, before the 4-hour duration course "Epilepsy and Education", given by the researchers (MSL and FPSS). The course was given through a classical live class, based on pedagogical implications of Ausubel's Meaningful Learning Theory[12] and its metacognitive tools, the Conceptual Maps,[13] to enable the meaningful learning and retaining of knowledge for more prolonged time. A group of 32 education professionals was assessed twice: before the epilepsy lecture and one month afterwards, with the aim of measuring its efficacy.

The primary objective was to measure the education professionals' knowledge about epilepsy and to estimate their level of stigma on epilepsy. The hypothesis is that after the course the knowledge on epilepsy would improve, and the level of perceived stigma decrease, measured by QAE and SSE.

The collected data were stored and analyzed with SPSS for Windows, Standard Version 17.0 (SPSS Inc., Chicago, IL, USA). After descriptive analysis of the socio-demographic variables, univariate statistical analysis consisted of Pearson's or Spearman's correlation tests for numerical parametric or non-parametric variables respectively were used to determine potential significant associations. The paired Student's t test was used to evaluate the results of SSE pre and post-course. A $p<0.05$ was considered significant.

The study was conducted according to Declaration of Helsinki, Institutional Ethics Committee approved the study and all subjects gave their informed consent before being interviewed.

RESULTS

This study evaluated 225 subjects. Their socio-demographic data (sex, age, educational degree, period employed in education and religion are discriminated in Tables 1 and 2.

Table 1 – Subjects evaluated in the study.

	Frequency	Percentage (%)
Teacher	97	43.1
Undergraduate student	67	29.8
Pedagogue	14	6.2
School administrative technician	41	18.2
Psychologist	3	1.3
Librarian	3	1,3

Table 2 – Subjects' demographic data.

Gender	
Men	79 (35.1%)
Women	146 (64.9%)
Age (years)	31.79±10.63 (18-60)*
Schooling (years)	14.49±2.60 (11-19)*
Time in education profession	10.00±9.27 (0-40)*
Religion[a]	120 (63.2%)
Catholic	9 (4.7%)
Spiritist	25 (13.2%)
Evangelical	9 (4.7%)
Other	27 (14.2%)
No religion	[a] Undeclared=35
Know someone with epilepsy	105 (46.7%)

* mean ± standard deviation (minimum and maximum).

QAE and SSE applied prior to the epilepsy course

Concerning the subject "Concepts, definitions and causes of epilepsy" there were more than 50% of correct answers. However, less than 50% of respondents were able to answer whether or not foods cause epilepsy and only 41.3% knew how to differentiate epilepsy from seizures. Most individuals answered correctly in the field "Treatment and medication adverse events". Few exceptions were the questions "If the person feel any side effect, the antiepileptic drug should be interrupted immediately" in which only 46.7% agreed and only 12.4% of respondents knew about the existence of epilepsy surgery offered by Brazilian public health care system. It is noteworthy that 24.2% of respondents did not know whether epilepsy may be treated by religious or spiritual interventions. Within the field "Stigma and popular knowledge about epilepsy" 51.1% of education professionals answered that nervousness can cause epilepsy and 42.75% of them did not know whether emotional trauma could cause epilepsy. Within the topic "Activities of people with epilepsy", only 42.7% of respondents knew that the person with epilepsy may have learning problems when epilepsy therapy is not appropriate. The majority, 43.1%, could not tell whether the person with epilepsy can drive. On the topic "First Aid during and after seizures" 65.3% of individuals would open the mouth of a person during a seizure in order to avoid tongue bites. Additionally, there was a general lack of knowledge about when it is necessary to refer a patient to the emergency department after a seizure.

The majority of professionals, 120 (53.3%), did not know any person with epilepsy and SSE mean score before the epilepsy course was 45.38±16.61 (minimum and maximum=8-86).

Furthermore, the older the professional, the lower the SSE score obtained ($r=-0.03$, $p<0.01$), as occurred when comparing length of employment in educational field with SSE ($r=-0.11$, $p<0.01$). More years of schooling resulted in lower scores on SSE ($r=0.02$, $p<0.01$). Participants who did not know anyone with epilepsy had a higher perception of stigma in epilepsy [Mean (M)=46.71; Standard deviation (SD)=16.23] than those who knew someone (M=43.74; SD=17.02). However, this difference was not significant at $t(188)=1.22$; $p=-0.089$.

Among the professions involved with education, the highest degree of stigma was found among Librarians [53.33±9.82 (34-66)], followed by Pedagogues [52.20±5.96 (26-86)], School Administrative Technicians [49.76±2.85 (20-84)], Undergraduate Students [43.85±1.82 (11-80)] and Teachers [43.41±2.04 (8-84)], while Psychologists demonstrated the most tolerant scoring average [32.67± 1.33 (30-34)].

Among different religious beliefs, the highest degree of stigma was recorded among Spiritualists 48.67±6.17 (25-79), while others presented SSE scores in decreasing order of intensity: 47.74±3.27 non-religious declared (20-86), Catholics 44.73±1.4 (8-84) and Evangelicals 44.72±3.75 (16-86).

QAE and SSE applied after the epilepsy course

The QAE and SSE were reapplied on 32 subjects after the epilepsy course to evaluate the acquisition of knowledge and eventual changes in perceived stigma. There was an increase in the level of epilepsy knowledge, evidenced by increased correct answers in all fields. It was still observed doubts concerning etiology of epilepsy, since only 40.6% of respondents agreed that "Any brain injury may lead to epilepsy". With respect to stigma and popular knowledge about epilepsy, 50.0% of respondents agreed that nervousness could cause epilepsy, and only 31.3% answered that this question was wrong. Similarly, only 46% answered that emotional trauma does not cause epilepsy. It is noteworthy to say that the concept that it is necessary to open the patient's mouth in order to avoid tongue bites decreased after the course, since 75% of respondents considered it a erroneous measure of relief to seizures.

The mean score of SSE after the course decreased to 37.38±13.41 (8-59), and it was statistically significant [$t(31)=-3.361$, $p<0,01$, r=0.52]. The epilepsy course caused a significant reduction in the perceived stigma in this particular population.

DISCUSSION

Epilepsy is the most common neurological condition in children, and may cause an enormous impact on their quality of life and may greatly influence the most distinctive aspects of their lives[14-16]. Several actions can be taken for improving the quality of life and psychosocial health of a person with epilepsy, such as a proper education and a welcoming school environment.

We observed that education professionals have some knowledge about epilepsy. However, there is a high degree of misconceptions regarding appropriate attitudes to be taken towards a person suffering from seizures and regarding its causes.

Previous studies demonstrated that teachers have a good knowledge about epilepsy due to their higher level of education. In Ojinnaka's (2002)[17] study, with 125 teachers, 37.6% of whom had university degree, but without any form of health education specifically for epilepsy, they had 59.2% of correct answers on questions about epilepsy proposed by the author. In Fernandes and cols' (2007)[18] study about the perception of teachers' knowledge about epilepsy, 43% of teachers claimed to have good knowledge about the disease and 20% had little knowledge, and pointed out that the greatest source of information about this condition were journal articles (53%), television (29%) and school (22%).

This study involved a group of education professionals with approximately 14 years of schooling. This finding is relevant because despite having higher educational levels, none of the participants had received any education directed towards epilepsy in their training years (considering more than 50% of accuracy for each proposition in the QAE). The level of knowledge found in our subjects may be considered inappropriate for an education professional, since important issues such as seizure recognition and basic knowledge in epilepsy were associated with a considerable number of errors.

Lack of knowledge about adequate assistance to seizures still persists, only 39.6% of respondents knew that seizures usually start and stop spontaneously, not requiring specific interventions such as calling to the emergency services in every seizure. Also 65.3% of respondents said that during a seizure one should open the mouth of the seizing person in order to prevent mouth injuries. This finding disagrees with the study of Guilhoto et al. (2007)[8] where only 35.71% of teachers would pull the tongue out of a person during a seizure. Perhaps this is due to the fact that in Guilhoto et al. (2007)[8] study, teachers had more teaching time (17.75 years) compared to ours where education professionals presented 10.0 ± 9.27 (0-40) years of profession. Also, in Guilhoto et al. (2007)[8] more than a half (61.53%) of the teachers knew someone with epilepsy, while in our study only 46.7% of education professionals knew someone with epilepsy. According to Bishop et al. (2006)[19] the most important factors related to teachers' knowledge about epilepsy were teaching time experience and the fact that they had taught a student with epilepsy.

One issue of concern was the lack of knowledge regarding different types of epileptic seizures. Only 47.6% of education professionals stated that seizures may originate from different areas of the brain and therefore may have different clinical manifestations, which may contribute to the non-recognition of seizures other than the generalized tonic-clonic ones in the classroom. In this same area, we found lack of knowledge about the origin of epilepsy. Only 13.8% of respondents knew that any neurological damage can lead to epilepsy and only 20.4% knew how to differentiate seizures from epilepsy. Additionaly, we noticed difficulties in distinguishing neurological symptoms and signs from psychiatric or psychological ones. Approximately half (51.1%) of the subjects believed that nervousness can cause epilepsy and 33.3% of them did not know what to answer. Similarly 32.4% felt that emotional trauma can cause epilepsy and 42.75% did not know what to answer.

In the field that is more directly related to education, which are the activities of people with epilepsy, there was a fair amount of correct answers (68.4%) when asked if the young person with epilepsy may practice sports – issue of importance for Physical Education teachers. The number of correct answers concerning that epilepsy is not usually associated with mental retardation was also satisfactory (73.3%). However, only 42.7% of respondents knew that people with epilepsy may have learning problems if they are not receiving correct treatment.

Stigma is a major issue for people with epilepsy and its reduction is the core of several global campaigns for people with epilepsy support[18]. Teachers are important role models or examples for children and therefore have an important influence on their lives[16]. Teachers' attitudes can influence the educational performance of the child, especially the child with epilepsy.[19] The perceived stigma degree in this population sample, quantified by SSE, was 45.38±16.61 (8-86). The value of the stigma score was slightly lower than the result found among the general community in the validation process of the scale which reached 46±18.22.[11] This difference can be explained by the nature of stigma, which is multifactorial.[20] There was not statistically significant association between perceived stigma and religion, gender, age and years of education or years of experience in education. Stigma is mainly associated with psychosocial variables[21]. People generally judge characteristics and behaviors of others relying on moral beliefs, cognitive processes and previous learning.[22-24]

As recommended in other studies,[8,10] one of the strategies for reducing stigma and erroneous knowledge on epilepsy is continuing education. In our study, after the questionnaires, all education professionals attended a 4 hours course on epilepsy with basic topics about epilepsy, necessary for someone who will deal with students suffering from this condition.

One month after the intervention, 32 teachers were reassessed by the QAE and SSE. The post-course results demonstrated a considerable increase on knowledge about epilepsy (above 50% of correct answers in the propositions) in all fields evaluated by the epilepsy questionnaire. However, it can be seen that consistent doubts about the concepts, definitions and causes of epilepsy still remains. Only 40.6% of respondents agreed to the issue “Any brain injury can lead to epilepsy”. In respect to stigma and popular knowledge about epilepsy, only 31.3% of respondents believed that nervousness does not cause epilepsy. Similarly, only 46% believed that emotional trauma does not cause epilepsy. This may be due to cultural difficulties, where there is confusion in determining what is neurological and psychiatric. This subject was extensively discussed during the course, however it seems to exist a strongly retained knowledge and difficult to modify. Another hypothesis is that the current approach used to correct these erroneous knowledge has not fulfilled its role.

An interesting fact is that the concept that is necessary to open the patient’s mouth was considered wrong by 75% of respondents. This issue was thoroughly discussed, with the exposure of the right attitude and also a short movie with wrong attitudes. This information confirms that it is essential to teachers to be informed how to support students with seizures appropriately. A teacher can imprudently, during a seizure, adopt disastrous attitudes to the student with epilepsy and also cause a bad impression to other students.

The mean score of SSE after the course was 37.38± 13.41 (8-59), significantly lower than the perceived stigma prior to the course. This result was lower than that found by Fernandes et al (2007d)[25] in a study on the perception of stigma with 1850 subjects in the state of São Paulo, 42±14. A better understanding of stigma may reduce teaches’ inappropriate reactions that limit meaningful experiences and the child normal affective-cognitive development.[26]

This study showed that a low cost, short duration course, based on a simple and pedagogically appropriate educational methodology, with scientific information and targeted to a specific audience, increased epilepsy knowledge and reduced the stigma among education professionals. It can contribute to a better care and well being of students with epilepsy and aiming at future psychosocial benefits.

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