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Assessment of knowledge and stigma regarding epilepsy among medical students at a brazilian educational institution: a pilot study.

PEDRO ANTÔNIO CUNHA CAMPOS[1], LAURA GALVÃO TAVARES[1], MARIA ALICE HORTA BICALHO[1], LUIZA PAIXÃO DE OLIVEIRA[1]

[1]FACULTY OF MEDICAL SCIENCES OF MINAS GERAIS (FCMMG) – BELO HORIZONTE, MG, BRAZIL

CORRESPONDING AUTHOR: PEDRO ANTÔNIO CUNHA CAMPOS – RUA CURITIBA, 1544- LOURDES, BELO HORIZONTE- MG, 30170-122, (+55) 37 991410054
EMAIL: PEDRO06042002@HOTMAIL.COM

ABSTRACT

Introduction: Epilepsy affects more than 50 million people worldwide. Despite its epidemiological relevance, it still carries a considerable stigma, severely impacting patients' quality of life. The literature demonstrates that such stigma is reproduced even among medical students. **Objectives:** To assess, through a questionnaire, the level of knowledge and the presence of stigma regarding epilepsy among medical students from a private educational institution. **Methods:** This was a pilot, cross-sectional study, conducted using an online questionnaire developed from previously validated instruments in Brazil. Eligible participants included medical students over 18 years of age enrolled at the institution of interest. **Results:** A total of 179 students participated, distributed across the preclinical (n=69), clinical (n=53), and internship (n=57) stages. The data collection period had to be extended due to low adherence, attributed to the questionnaire length. Stigma was identified in 63%, predominantly among students in the preclinical stage (44%). Moreover, a significant association was found between lower knowledge levels and the presence of stigma (p=0.017). Notably, 22% of students considered epilepsy to be a symptom of mental illness, 11% deemed it appropriate to introduce objects into the oral cavity during a seizure, and 6.7% reported they would not marry someone with epilepsy. **Conclusion:** The findings reveal a significant lack of knowledge about epilepsy among medical students, which was associated with higher levels of stigma in this sample. Further studies with larger samples are necessary to validate these results, potentially requiring a reduction in the number of questions included in the questionnaire.

Keywords: Epilepsy; Neurology; Knowledge; Social Stigma; Medical Students.

INTRODUCTION

Epilepsy is a serious neurological disorder, defined by the International League Against Epilepsy (ILAE) as a brain disease characterized by a persistent predisposition to generate epileptic seizures, with neurobiological, cognitive, psychological, and social consequences. It is an epidemiologically relevant condition, affecting more than 50 million individuals worldwide, of which 40 million cases (over 80%) occur in developing countries, including Brazil.[1,2]

The recognition that an epilepsy diagnosis carries psychosocial consequences can be better understood through a historical–cultural perspective.[3] The disease has long been highly stigmatized: since Ancient Greece, it was linked to supernatural phenomena and hysteria.[3] For instance, in Germany during the Nazi regime, the "Law for the Prevention of Offspring with Hereditary Diseases" was enacted in 1933, which explicitly included measures to prevent people with epilepsy (PWE) from having children, even through forced sterilization.[3] In the United Kingdom, laws prohibiting marriage with PWE were only revoked in 1970.1 In India, less than 30 years ago, marriages could still be annulled if either spouse presented episodes of insanity or epilepsy. Until 1999, epilepsy not only allowed annulment but also rendered a marriage legally invalid in that country.[3]

A recent study[4] involving a sample of 256 PWE found that 39.8% reported feeling stigmatized due to epilepsy. Such stigmatization affects family and social life, employment, marital prospects, and self-esteem,[5,6] often leading patients to hide their condition, avoid medical consultation, and fail to adhere to treatment, ultimately contributing to worse prognoses.[1] Furthermore, the impact on mental health is particularly relevant.[7,8,9] Depression is the most common psychiatric comorbidity among PWE, with up to one-third experiencing depressive disorder.[10] A meta-analysis[11] revealed that the mortality rate from suicide is three times higher in PWE compared with the general population (standardized mortality ratio: 3.25; 95% CI: 2.81–3.75). Another cross-sectional study with 267 participants demonstrated a positive association between perceived stigma and depression severity, as well as between depression severity and suicide risk.[12]

It is important to highlight that stigma is closely associated with poor knowledge about epilepsy, which is considered a determinant of social rejection of PWE.[13,14] Despite the clinical and epidemiological relevance of epilepsy, studies among students and healthcare professionals continue to demonstrate knowledge gaps regarding the disease.[15-20] This paradox, whereby future healthcare providers also reveal limited knowledge about epilepsy, is exemplified by a cross-sectional study among Saudi university students, in which 20% attributed the condition to spiritual possession or mental disorders.[15] Similarly, an Italian study among medical students and professors found that 41.1% attributed psychological causes to epilepsy, 43.9% of professors considered the disease incurable, and over 40% of both students and professors reported they would insert objects into the mouth of a patient during a convulsive seizure.[16]

Thus, there appears to be a substantial lack of knowledge about epilepsy among medical students, both in relation to the disease's etiology and to the appropriate management of affected patients. This gap perpetuates the centuries-old stigma and hinders meaningful change, especially considering that these students will become future healthcare providers for this population. Considering this context and the limited number of Brazilian studies on the topic, the present research aims to evaluate the level of knowledge and the presence of stigma among medical students. In addition, it investigates the relationships among these variables, compares results across different stages of medical training, and examines the applicability of the authors' adapted questionnaire.

METHOD

Study design

This pilot cross-sectional study evaluated medical students' knowledge about epilepsy and the degree of stigma associated with the condition at a private educational institution. Data were collected through an online questionnaire distributed via "Google Forms" to medical students from the 1st to the 12th semester. Data collection began after approval by the Research Ethics Committee (CEP) of Ciências Médicas de Minas Gerais in July 2023. All ethical principles were respected, in accordance with Resolution 466/12 of the Brazilian National Health Council. The project was approved (approval number 6.161.761), and the questionnaire was administered between February and August 2024.

Sample

Participants were medical students over 18 years of age from a private institution in Belo Horizonte who signed written informed consent. A convenience sampling strategy was adopted, and students who did not fully complete the questionnaire were excluded. Sample size calculation was performed using a one-way ANOVA model, with an effect size of 0.15, a significance level of 0.05, a test power of 0.80, and three group levels, using G*Power software, version 3.1.9.7. The result was a total sample size of 432 participants. Based on the proportional distribution of students across the medical program, the estimated sample was redistributed as follows: 150 (35%) in the preclinical stage, 143 (33%) in the clinical stage, and 139 (32%) in the internship. Since this was a pilot study, data collection was discontinued once more than 30% of the intended sample size had been reached in each phase of medical training.

Instruments and procedures

The primary instrument used in this study was a questionnaire comprising 37 items adapted by the authors and administered through "Google Forms". It was based on previously validated instruments used in studies conducted in Brazil.[17,18] Knowledge about epilepsy was assessed using an adapted version of the "Epilepsy Knowledge Questionnaire" (EKQ), validated in Portuguese,[17] originally developed by Jarvie et al. (1993). The original instrument consists of 55 true/false/"don't know" items. For the present study, the questionnaire was reduced to 12 items, and the term "convulsion" was replaced with "epileptic seizure." Stigma was assessed using the Epilepsy Stigma Scale (ESS), validated in Brazil,[18] which consists of 24 items with four possible responses: 1 = No, 2 = A little, 3 = Quite a lot, 4 = Very much. The items were scored using the following formula, resulting in values ranging from zero (absence of stigma) to 100 (maximum stigma):

$$\frac{(\text{Sum of all item scores} - \text{Number of items answered}) \times 100}{\text{Maximum possible score} - \text{Minimum possible score}}$$

Stigma was classified as present when the ESS score was ≥50, and absent when <50. Additionally, one question regarding willingness to marry someone with epilepsy was added to the instrument. Responses were categorized according to the stage of medical training: preclinical (1st–4th semesters), clinical (5th–8th semesters), and internship (9th–12th semesters). Comparisons were then made across stages, enabling associations among knowledge level, stigma, and training level.

Statistical analysis

After collection via Google Forms, the data were anonymized, logged into "Microsoft Excel" spreadsheets, and analyzed using R software, version 3.2.1. Qualitative variables were presented as absolute and relative frequencies, while quantitative variables were summarized by median and interquartile range. Normality was tested for quantitative variables. Variables with normal distribution were analyzed using Student's t test, while those without normal distribution were analyzed using the Mann–Whitney test. Associations between qualitative variables were assessed using the chi-square test or Fisher's exact test. The significance level was set at 5%.

RESULTS

The final sample included 179 medical students, with a median age of 22 years. Of these, 69 were in the preclinical stage, 53 in the clinical stage, and 57 in the internship. A detailed description is presented in Table 1.

Table 1. Sociodemographic characteristics of the total sample and stratified by stage of medical training.

VARIABLES	TOTAL	STAGE		
		PRECLINICAL	CLINICAL	INTERNSHIP
NUMBER OF PARTICIPANTS	179	69 (38%)	53 (30%)	57 (32%)
MEAN AGE (YEARS)	22.3	21	22.3	23.5
MEDIAN AGE (YEARS)	22 (20-23)[1]	20 (19-22)[1]	22 (21-23)[1]	22 (22-23)[1]

[1]Median, interquartile range, (Q1-Q3)

Study variables were categorized according to previously published studies and the investigator's expertise. As defined above, stigma was considered present when the ESS score was ≥50 and absent when <50. Knowledge levels were categorized as high, moderate, or low according to the percentage of correct responses: high (>80%), moderate (60-80%), and low (<60%). Responses marked as "don't know" were classified as incorrect, as they indicated insufficient knowledge to answer the item.

In light of this categorization, the main results obtained are described below:

Table 2. Stigma identified in the total sample.

STIGMA	SAMPLE (n=179)
Present	113 (63%)
Absent	66 (37%)

Table 3. Stigma by stage of medical training.

	STIGMA		
	ABSENT N = 66	PRESENT N = 113	p-value[1]
STAGE OF MEDICAL TRAINING			**0.001**
PRECLINICAL STAGE	19 (29%)	50 (44%)	
CLINICAL STAGE	15 (23%)	38 (34%)	
INTERNSHIP	32 (48%)	25 (22%)	

[1] Pearson's chi-square test of independence.

Table 4. Level of knowledge in the total sample and by stage of medical training.

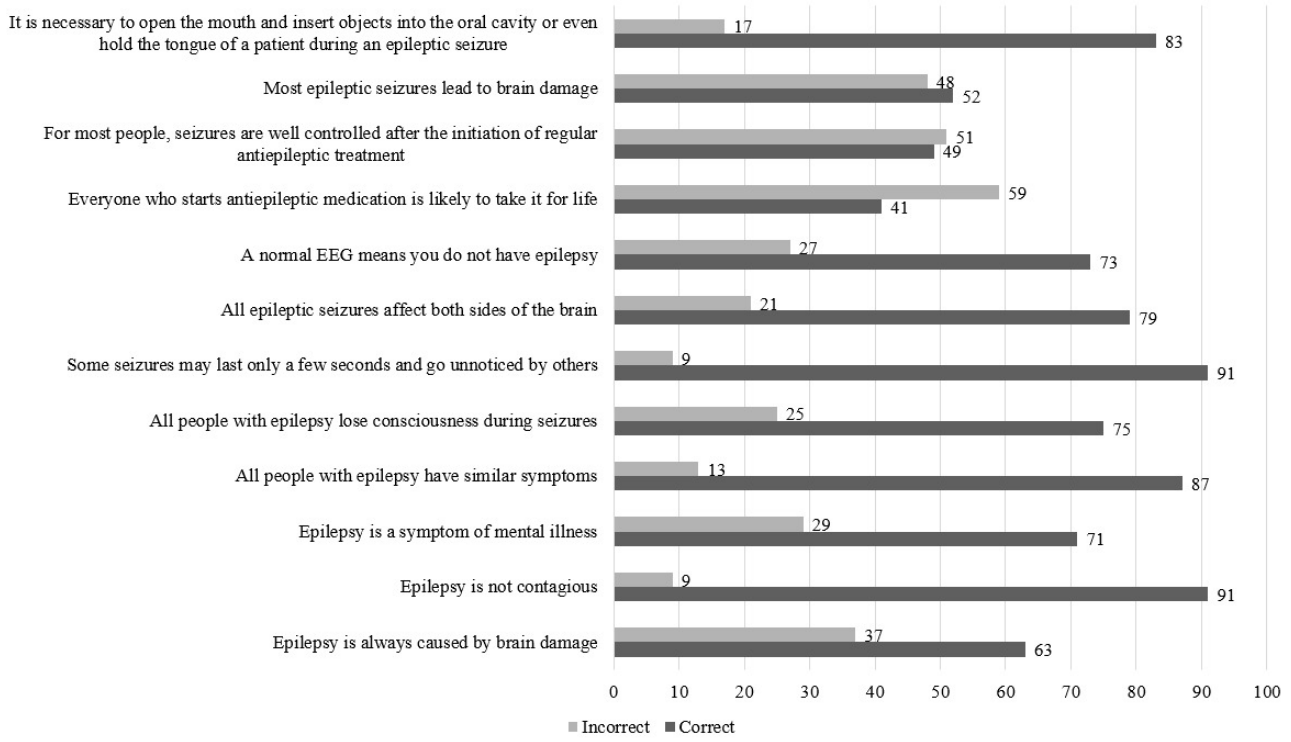
KNOWLEDGE LEVEL	TOTAL (n=179)	STAGE		
		PRECLINICAL (n=69)	CLINICAL (n=53)	INTERNSHIP (n=57)
LOW	52 (29%)	39 (57%)	8 (15%)	5 (9%)
MEDIUM	54 (30%)	16 (23%)	21 (40%)	17 (30%)
HIGH	73 (41%)	14 (20%)	24 (45%)	35 (61%)
MEAN ACCURACY (%)	71%	59.2%	76.1%	81.3%

Tabela 5. Stigma by level of knowledge.

		KNOWLEDGE LEVEL			
	TOTAL N = 179	LOW N = 52	MEDIUM N = 54	HIGH N = 73	p-value[1]
STIGMA					**0.017**
PRESENT	113 (63%)	40 (77%)	35 (65%)	38 (52%)	
ABSENT	66 (37%)	12 (23%)	19 (35%)	35 (48%)	

Pearson's chi-square test of independence.

Figure 1. Percentage of correct and incorrect answers to questions related to knowledge about epilepsy.



It is worth highlighting some questionnaire findings. For item 2 ("Epilepsy is not contagious"), 8.4% (n=15) of participants considered the statement to be false, including 12% (n=8) in the preclinical stage and 9% (n=5) in the internship. For item 3 ("Epilepsy is a symptom of mental illness"), 22% (n=40) of participants regarded the statement as true, with 29% (n=20) in the preclinical stage versus 9% (n=5) in the internship. For item 12 ("It is necessary to open the mouth and insert objects into the oral cavity or even hold the tongue of a patient during an epileptic seizure"), 11% (n=19) of students marked the option "True," including 19% (n=13) in the preclinical stage versus 4% (n=2) in the internship. Finally, 6.7% (n=12) of medical students stated they would not marry an individual with epilepsy.

DISCUSSION

Aspects related to knowledge about epilepsy

The overall mean percentage of correct responses regarding knowledge about epilepsy in this study was 71%. However, when analyzed individually, only 41% of medical students achieved a high level of knowledge. On a positive note, as students progressed through the program, their mean accuracy scores increased: 59.2% in the preclinical stage, 76.1% in the clinical stage, and 81.3% in the internship.

These findings are consistent with the literature. A multicenter study conducted in 2018, which also applied the complete version of the EKQ and included 41 Brazilian health science students within a total sample of 102 participants, reported a mean accuracy of 67% in the overall sample and 68% among Brazilian participants.[17]

Nevertheless, some concerning findings emerged regarding medical students' knowledge about epilepsy. In our sample, 22% perceived epilepsy as a symptom of mental illness, a misconception most frequently observed among students in the preclinical stage. By contrast, a Brazilian study conducted in 2004[19] reported that only 10% of first-year health science students shared this perception, dropping to 7% by the final year. In comparison, the aforementioned multicenter study[17] reported an even higher percentage, at 34%. Likewise, a study conducted in Sudan[20] with senior medical students found that 62.7% attributed psychological causes to epilepsy. Although more severe scenarios have been documented, our findings still reveal that more than one in five respondents associated epilepsy with mental disorders.

Another point to be considered is the misconception that epilepsy is contagious. In our study, 8.4% of students held this belief, a result comparable to that reported by Souza et al.,[17] where 10% of participants shared the same misconception.

Regarding the practice of inserting objects into the mouth of patients during an epileptic seizure, 11% of participants endorsed this conduct. Importantly, this proportion declined substantially as students advanced through the program, from 19% in the preclinical stage to only 4% during the internship. Although these numbers remain relatively high, they are favorable when compared to another Brazilian study,[19] in which 71% of first-year health science students and 32% of final-year students agreed with the practice. Studies conducted with health science students in other countries, such as Saudi Arabia,[21] Sudan,[20], and Italy,[16], also reported higher proportions than those found in our study: 35.6%, 54.4%, and 47%, respectively.[16,20,21]

Aspects related to stigma toward epilepsy

Stigma was identified in 63% of the participants who completed the questionnaire. Notably, stigma decreased as students advanced through the program: it was present in 44% of students in the preclinical stage, 34% in the clinical stage, and 22% in the internship. Within the items of the ESS, the most frequently reported limiting factors for PWE, and those contributing most to higher stigma scores, were concerns about the disease, emotional problems, and prejudice in daily life. Specifically, 92% of students considered that PWE feel quite or very worried about their condition, while 80% believed that PWE experience considerable or extreme difficulty in daily life due to emotional issues and discrimination.

Additionally, 6.7% of medical students reported that they would not marry an individual with epilepsy. Similarly, another Brazilian study[19] found values of 4% among first-year students and 5% among final-year students. In contrast, an Italian study[16] including 667 professors and 672 health science students found that 25.6% of the former and 37.5% of the latter indicated limitations regarding marriage with PWE. These data highlight that, even in intellectually privileged groups, stigmatized views of epilepsy may manifest in partner selection. Thus, stigma clearly impacts multiple dimensions of the lives of PWE, including relational and emotional aspects, leading to discriminatory and exclusionary behaviors.

Association between stigma and level of knowledge

Furthermore, the relationship between stigma and level of knowledge was statistically significant in our study ($p=0.017$), supporting the hypothesis of an inverse correlation between these variables: the lower the level of knowledge, the higher the potential for stigmatized views. For instance, among those with low levels of knowledge, 77% exhibited stigma, compared with 52% among those with high levels of knowledge.

Aspects related to the questionnaire

The instruments selected to support the questionnaire used in this study had already been validated in Brazil

by Souza et al. and Fernandes et al.,[17,18] but had not previously been applied to the same type of sample. Although the knowledge section (EKQ) underwent a significant reduction in the number of items (from 55 to 12), when combined with the stigma section (ESS), it resulted in an extensive instrument of 37 items, which hindered data collection within the timeframe initially envisioned by the researchers. The data collection period had to be extended from four to seven months, with multiple in-person calls for participation, due to low adherence attributed to the large number of questions, particularly in the stigma section, which contained 24 items. Completion time exceeded 10 minutes, which was contrary to the researchers' initial expectations. While the instrument employed in this study provided the intended information, its length negatively impacted student participation. Thus, it may be necessary to reassess the number of questions for future applications in larger samples.

Nevertheless, it is important to emphasize the instrument's ability to demonstrate the knowledge gap regarding epilepsy, which was significantly associated with the degree of stigma observed. In this sense, the questionnaire highlights the need to adapt medical curricula to address this exclusionary reality. Critical and well-grounded medical education about epilepsy would serve as an essential tool to counter stigmatizing beliefs and potentially improve the quality of life of people with epilepsy, considering that medical students are the future providers of care for this vulnerable patient population.

LIMITATIONS

This was a pilot study conducted with a convenience sample, which may not be representative of the target population. The students who completed the questionnaires may have been those most interested in the subject, potentially leading to an underestimation of stigma. Moreover, it was not possible to ensure that participants did not verify or confirm their answers before submission, since the questionnaire was administered online.

CONCLUSION

Epilepsy has historically been a highly stigmatized condition. Lack of knowledge is a key factor in the perpetuation of this outdated perception, and even within samples of healthcare professionals, the literature demonstrates persistent challenges in overcoming this barrier. The present study revealed an overall moderate level of knowledge about epilepsy among medical students, although stigma was still present in the majority of respondents. When stratified by stage of training, more advanced students achieved higher percentages of correct answers and exhibited lower levels of stigmatization. A statistically significant association was observed between knowledge and stigma, reinforcing the finding that lower knowledge levels are linked to a higher likelihood of stigmatized views.

These results highlight the potential need to strengthen epilepsy-related content in medical education to mitigate prevailing stigmatizing attitudes. Given the relevance of the findings and the scarcity of similar Brazilian studies, further research with larger samples is warranted, potentially requiring a reduction in the number of items in the questionnaire. Training medical students to be well-prepared and equipped to manage epilepsy without discrimination is an essential step toward meaningful change in the current scenario.

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