

Epilepsy awareness among Rabigh Province residents in Saudi Arabia: A cross-sectional survey study

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ABSTRACT

الأهداف: تبحث هذه الدراسة في المعرفة والمواقف تجاه الصرع في محافظة رابغ غربي المملكة العربية السعودية.

المنهجية: أجريت دراسة مقطعية مستعرضة قائمة على المسح في الفترة من يوليو إلى سبتمبر 2020م. تم توزيع المسح عبر شبكة الإنترنت على عموم السكان في محافظة رابغ. تم تقدير درجة الوعي بالصرع (EAS) باستخدام استبيان تم إنشاؤه.

النتائج: عدد المشاركين هو 511. معظم المشاركين لم يعرفوا ما هي الإجراءات التي يجب اتخاذها عند حدوث نوبة بخلاف إبعاد الشخص عن الأذى (87%). المشاركون الذين اتفقوا على أن الصرع موصوم بدرجة عالية يمثلون 15%. كان المشاركون يرفضون (27%) أو مترددون بشأن رد فعلهم (34%) إذا كان طفلهم سيتزوج من شخص مصاب بالصرع. الغالبية لا تمنع إذا كان أطفالهم يتعايشون مع مصاب بالصرع. كان بعض الآباء قلقين بشأن جعل أطفالهم يلعبون أو يرتبطون بمصاب بالصرع. توجد ارتباطات ذات دلالة إحصائية بين EAS والعمر ($p=0.03$)، والدخل الشهري ($p=0.03$)، وإيجاب الأطفال ($p=0.04$).

الخاتمة: كانت البيانات الموجودة في هذه الدراسة مشابهة للدراسات السعودية والعالمية الأخرى. هناك حاجة إلى مزيد من الجهود لتعزيز وعي المجتمع بشأن الصرع. تؤثر وصمة العار في المجتمع على المصابين وتؤثر على أحبائهم أيضاً. لذلك، هناك حاجة إلى حملات تثقيفية تكميلية للتطبيق وخلق القبول. أيضاً، لزيادة الوعي فيما يتعلق بالإسعافات الأولية للصرع.

Objectives: To investigate the knowledge and attitudes toward epilepsy in Rabigh province in western Saudi Arabia.

Methods: A cross-sectional survey-based study was conducted from July to September 2020. Survey was distributed through the web to Rabigh province general population. Epilepsy awareness score (EAS) was estimated utilizing a generated questionnaire.

Results: The number of participants is 511. Most participants did not know what actions to take for an active seizure other than moving the person away from harm (87%). Participants who agreed that epilepsy was highly stigmatized represented 15%. Participants were refusing (27%) or undecided about their reaction (34%) if their child were to marry an epilepsy person (EP). The majority did not mind if their children socialized with EP. Some parents were anxious about having their children play or associated with EP. There are statistically significant associations between EAS and age ($p=0.03$), monthly income ($p=0.03$), having children ($p=0.04$).

Conclusion: The data found in this study was similar to other Saudi and global studies. Further efforts are needed to strengthen community awareness regarding epilepsy. Stigma in society affects those that are afflicted and has consequences on their loved ones as well. Therefore, supplementary educational campaigns are needed to normalize and create acceptance. Also, to increase awareness regarding first aid of epilepsy.

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Globally, approximately 70 million (1-2%) people suffer from epilepsy, a neurological condition that predisposes the affected individual to have recurrent seizures.¹ As defined by the International League Against Epilepsy (ILAE), a patient is required to have

2 unprovoked seizures at least 24 hours apart to be labeled as having the disease.² Cryptogenic or idiopathic seizures account for approximately 50% of those with epilepsy while sociodemographic factors may play a role in prognosis and outcome.^{3,4} Although little is known regarding epilepsy prevalence in Saudi Arabia (SA), a study conducted in 2001 approximated the prevalence in the country to be 6.54 per 1000 population.⁵

Locally, the awareness and attitude regarding epilepsy across various major cities in different regions of SA showed that public knowledge regarding the condition was insufficient for the past several years.^{6,7} Rabigh province, is a province that growing and transforming into a more urbanized area. There are multiple main projects of SA in this province like King Abdullah Economic City, King Abdullah University for Science & Technology, Aramco (Arabian American Oil Company) refinery, and Petro-Rabigh plant which is one of the biggest and sophisticated plants in SA and the world.⁸ This study aims to assess the awareness and attitudes of a local population regarding epilepsy in the Western region of SA and to compare the results with previous studies.

Methods. A cross-sectional, population-based study conducted through an online survey disseminated amongst residents of the Saudi province of Rabigh from July to September 2020. The survey was spread via social media dedicated to Rabigh Province and the students in Rabigh King Abdulaziz University. The inclusion criteria are working in Rabigh province and age above 18 years old. We exclude persons with history of epilepsy and persons live outside Rabigh for more than 2 days per week. Ethical approval was obtained from the Research Ethics Committee of the Faculty of Medicine at King Abdulaziz University in Jeddah, Saudi Arabia and the guidelines outlined in the Declaration of Helsinki were followed.

Previous studies regarding epilepsy awareness in Saudi Arabia and specially in Rabigh province, in the last 5 years were searched in google scholar and PubMed using the keywords: Epilepsy, Awareness/Knowledge/Attitude, Saudi Arabia, and Rabigh.

The questionnaire consists of 4 sections: respondent demographics, epilepsy background, epilepsy knowledge, and attitude toward epilepsy. Demographics

included information about gender, age group, nationality, marital status, level of education, monthly income, being diagnosed with epilepsy, family history of epilepsy, and occupation. Epilepsy background questions asked respondents whether they have ever read of convulsive seizures, seen or known anyone with or have had an active seizure, know what to do, or have received first aid training in the management of epilepsy. The epilepsy knowledge section consisted of a series of questions to assess the respondent's level of comprehension regarding what to do during a seizure attack, the causes of epilepsy, treatment options, and abilities of those affected by the disease.

Table 1 - Demographics.

Characteristics	n (%)*
<i>Gender</i>	
Male	271/511 (53)
Female	240/511 (47)
<i>Age</i>	
Mean±SD	32.76±10.813
Minimum–Maximum	18-60
<i>Age Group</i>	
18-29	233/511 (45.6)
30-55	263/511 (51.5)
>55	15/511 (2.9)
<i>Marital Status</i>	
Married	311/511 (60.9)
Single	200/511 (39.1)
<i>Do you have children?</i>	
Yes	277/507 (54.6)
No	230/507 (45.4)
<i>Educational Level</i>	
Elementary School	1/511 (0.2)
Middle School	13/511 (2.5)
High School Diploma	151/511 (29.5)
Diploma	44/511 (8.6)
Bachelor's Degree	292/511 (57.1)
Master's Degree	8/511 (1.6)
Doctoral Degree	2/511 (0.4)
<i>Monthly income</i>	
<5,000 SR	227/511 (44.4)
5,000-10,000 SR	147/511 (28.8)
>10,000 SR	137/511 (26.8)
<i>Occupation</i>	
Physician	14/511 (2.8)
KAU ^a Rabigh Medical Student	81/511 (16.1)
KAU ^a Rabigh Student	55/511 (10.9)
High school teacher	24/511 (4.8)
Middle school teacher	11/511 (2.2)
Elementary school teacher	13/511 (2.6)
Freelance	32/511 (6.3)
Unemployed	113/511 (22.4)
Other	161/511 (31.9)

*Percentages may not equal 100% due to rounding, ^aKing Abdulaziz University

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Table 2 - Participants' background on epilepsy.

	n (%)
<i>Have you ever read about epilepsy or "convulsive seizures" (fits)?</i>	
Yes	463/511 (90.6)
No	48/511 (9.4)
<i>Do you know anyone who has epilepsy?</i>	
Yes	0/511 (0)
No	455/511 (89)
I don't know	56/511 (11)
<i>Have you ever seen anyone having an active seizure?</i>	
Yes	286/511 (56)
No	202/511 (39.5)
I don't know	23/511 (4.5)
<i>Do you know what to do if someone is having a seizure in front of you?</i>	
Yes	171/511 (33.5)
No	266/511 (52.1)
I don't know	74/511 (14.5)
<i>Have you ever received first aid training regarding the management of epilepsy?</i>	
Yes	116/511 (22.7)
No	395/511 (77.3)

The last portion of the questionnaire aimed to assess the attitude of the respondents towards epilepsy. The questions were generated from validated questionnaire of previous studies conducted in Saudi Arabia in 2019 and above.^{7,9-13}

An epilepsy awareness score (EAS) was generated for each correct answer from the epilepsy knowledge portion of the questionnaire. Zero points were given for a wrong answer, "I don't know", or a blank. The score was out of 45 total questions.

The survey data used in this study are available upon request from the corresponding author. Statistical analysis was carried out using IBM SPSS Statistics Version 20. Pearson's Correlation Coefficient is used

to investigate the linear association between two continuous variables. Analysis of variance (ANOVA) and independent samples t-test were used to investigate the association between the means of the study variables as appropriate. The significance level was taken at <0.05 with a 95% confidence interval (CI).

Results. Demographic data. A total of 511 people volunteered to participate in the survey. 53% were male and 47% were female. The majority (51.5%) were between 30–55 years of age and approximately two thirds (60.9%) were married with a little more than half (54.6%) answering that they had children. Although the great majority (57.1%) held a bachelor's degree, 44.4% had a monthly income less than 5000 Saudi Riyals and 22.4% were unemployed. Most of the participants live in Rabigh city (61.4%) and 23.7% came from another province, but currently live in Rabigh province. All the study participants denied personal history of epilepsy and 29.4% admitted to family history of epilepsy. Detailed demographic data is displayed in Table 1.

Epilepsy background. Regarding participants' epilepsy background, 90.6% claimed to have read about convulsive seizures and 56% responded they have seen an active seizure before. Only 171 of those who responded (33.5%) stated to know what to do if someone is seizing, however just 22.7% stated that they received first aid training regarding epilepsy management. Further information regarding respondent's answers can be seen in Table 2.

Epilepsy knowledge. Regarding first aid knowledge, during an active seizure, 87.3% of participants knew that it was correct to move a seizing person away from

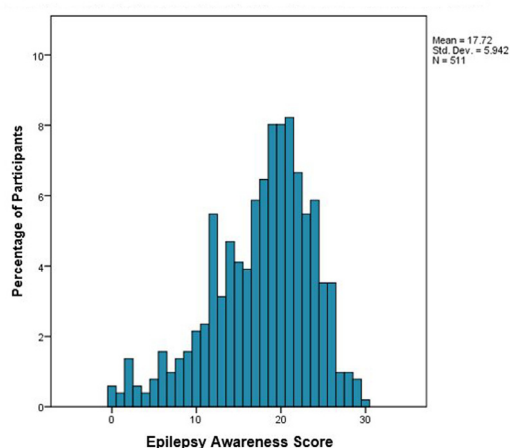
**Figure 1** - Epilepsy awareness score distribution among participants

Table 3 - Participants' knowledge about epilepsy and first aid of epilepsy.

Questions (n)	Correct answer	Correct answer n (%)	Incorrect answer n (%)	Don't know n (%)
1. If someone is seizing, should you: (511)				
-Promptly move them away from danger?	Yes	446 (87.3)	18 (3.5)	47 (9.2)
-Put a spoon or cloth in their mouth?	No	146 (28.6)	206 (40.3)	159 (31.1)
-Force their medication in their mouth?	No	312 (61.1)	26 (5.1)	173 (33.9)
-Splash water on them?	No	165 (32.3)	224 (43.8)	122 (23.9)
-Hold/ fix them so they can't move?	No	101 (19.8)	320 (62.6)	90 (17.6)
2. Do you think epilepsy affects: (506)				
-all ages?	Yes	406 (79.5)	20 (3.9)	80 (15.7)
-sexual ability?	Yes	95 (18.6)	118 (23.1)	293 (57.3)
-pregnancy?	Yes	156 (30.5)	99 (19.4)	251 (49.1)
-lifespans?	No	62 (12.1)	218 (42.7)	226 (44.2)
3. An Epilepsy attack is: (506)				
-convulsion or shaking	Yes	436 (85.3)	12 (2.3)	58 (11.4)
-loss of consciousness	Yes	383 (75)	66 (12.9)	57 (11.2)
-transient change of behavior	Yes	209 (40.9)	142 (27.8)	155 (30.3)
-period of amnesia	Yes	194 (38)	129 (25.2)	183 (35.8)
-blank staring	Yes	235 (46)	103 (20.2)	168 (32.9)
-headache	No	122 (23.9)	190 (37.2)	194 (38)
-hallucination	No	159 (31.1)	143 (28)	204 (39.9)
4. Epilepsy is a form of insanity (506)				
	No	413 (80.8)	27 (5.3)	66 (12.9)
5. What do you think is the cause of epilepsy? (506)				
-Hereditary/ Genetic disease	Yes	307 (60.7)	69 (13.6)	130 (25.7)
-Infectious/ Contagious disease	No	429 (84.8)	6 (1.2)	71 (14.0)
-Brain disorder or injury	Yes	391 (77.3)	17 (3.4)	98 (19.4)
-Birth defect	No	151 (29.8)	181 (35.8)	174 (34.4)
-Mental or emotional disorder	No	154 (30.4)	164 (32.4)	188 (37.2)
-Blood disorder	No	304 (60.1)	24 (4.7)	178 (35.2)
-Devil Spirit	No	273 (54.0)	98 (19.4)	135 (26.7)
-Witchcraft	No	272 (53.8)	92 (18.2)	142 (28.1)
-Evil Eye	No	234 (46.2)	136 (26.9)	136 (26.9)
-Punishment from God	No	287 (56.7)	25 (4.9)	194 (38.3)
6. If your relatives have epilepsy, what would you suggest for them to do? (506)				
-Ask for medical advice	Yes	484 (95.7)	3 (0.6)	19 (3.8)
-Ask for herbal treatment	No	296 (58.5)	126 (24.9)	84 (16.6)
-Get medication from a drugstore	No	273 (54.0)	174 (34.4)	59 (11.7)
-Go to a spiritual healer	No	384 (75.9)	54 (10.7)	68 (13.4)
-Tell them epilepsy is not treatable	No	322 (63.6)	46 (9.1)	138 (27.3)
-Tell them there is no need for treatment	No	426 (84.2)	15 (3.0)	65 (12.8)
-Treat them with religious supplications	No	89 (17.6)	333 (65.8)	84 (16.6)
-tell them to try wet cupping	No	194 (38.3)	155 (30.6)	157 (31.0)
-tell them to try traditional cauterization	No	279 (55.1)	73 (14.4)	154 (30.4)
-tell them to try camel extracts	No	288 (56.9)	37 (7.3)	181 (35.8)
7. Is there a role for surgical intervention for advanced epilepsy? (506)				
	Yes	165 (32.6)	66 (13.0)	275 (54.3)
8. Should people with epilepsy be				
-employed like other people without epilepsy? (501)	Yes	309 (61.7)	102 (20.4)	90 (18.0)
-isolated from society?	No	481 (96.0)	6 (1.2)	14 (2.8)
9. Can people with epilepsy be active members of society? (501)				
	Yes	467 (93.2)	15 (3.0)	19 (3.8)
10. Are the mental abilities of those epilepsy the same as those without epilepsy? (501)				
	Yes	469 (93.6)	12 (2.4)	20 (4.0)
11. Can a child with epilepsy be successful in a normal class? (501)				
	Yes	444 (88.6)	10 (2.0)	47 (9.4)
12. Can a patient with controlled epilepsy drive a car? (501)				
	Yes	185 (36.9)	185 (36.9)	131 (26.1)
13. Are epilepsy patients stigmatized in society?(501)				
	Yes	73 (14.6)	188 (37.5)	240 (47.9)

Table 4 - Participants' attitude toward epilepsy.

Statements	n (%)
<i>Would you befriend someone with epilepsy?</i>	
Yes	424/501 (84.6)
No	18/501 (3.6)
I don't know	59/501 (11.8)
<i>Would you object to having any of your children associated with a person who has seizures at school?</i>	
Yes	52/501 (10.4)
No	376/201 (75)
I don't know	73/501 (14.6)
<i>Would you object to having your children play with a child who has seizures?</i>	
Yes	48/501 (9.6)
No	389/501 (77.6)
I don't know	64/501 (12.8)
<i>Would you object to your children marrying someone who has seizures?</i>	
Yes	137/501 (27.3)
No	196/501 (39.1)
I don't know	168/501 (33.5)
<i>Would you lie about having a family member with epilepsy?</i>	
Yes	10/501 (2)
No	467/501 (93.2)
I don't know	24/501 (4.8)

danger. However, almost one third (33.9%) were not sure whether to force the patient to take their medication, force a spoon or cloth in their mouth (31.1%), splash water on them (23.9%), and 62.6% answered incorrectly that they should hold or fix the seizing person, so they are unable to move.

Most participants (406/506) knew that epilepsy affects all ages, and 62% knew that it did not affect lifespan. However, participants were not sure if epilepsy has effects on sexual ability or pregnancy. The following symptoms were correctly recognized as symptoms of Epilepsy: convulsion or shaking (85.3%), loss of consciousness (75%), transient change of behavior (40.9%), period of amnesia (38%), and blank staring (46%). On the other hand, headache (37.2%) and hallucination (28%) were incorrectly recognized as symptoms of Epilepsy among some respondents, while 5.3% thought epilepsy was a form of insanity.

The cause of epilepsy was correctly identified as hereditary or genetic (60.7%) or a result of brain disorder or injury (77.3%). Incorrect answers included epilepsy being caused by mental disorders (32.4%), devil spirits (19.4%), blood disorders (4.7%), birth defects (3.4%), and contagious disease (1.2%).

Treatment options were correctly recognized as medical (95.7%) and surgical (32.6%) in some cases. However, some incorrectly felt there was a role for herbal treatment (24.9%), over the counter medications (34.4%), wet cupping (30.6%), spiritual healers (10.7%) and 9.1% believed that epilepsy is not

treatable, with 3% believing that there is no need for any sort of treatment.

The majority (93.2%) recognized that people with epilepsy can be active members of society and although 93.6% recognized that the mental abilities of those with epilepsy are the same as those without epilepsy, only 61.7% thought they should be employed like those without epilepsy. Detailed questionnaire data regarding epilepsy knowledge can be found in Table 3.

Attitude toward epilepsy. Among participants, 84.6% replied that they would befriend someone with epilepsy, 75% would not object to having their children associated with a person with seizures at school, and 77.6% would not object to their children playing with a child known to have seizures. Regarding their children marrying someone with epilepsy, only 39.1% said they would not object, and 2% replied that they would lie about having a family member with epilepsy. Table 4 shows detailed respondent answers on attitude toward epilepsy.

Epilepsy awareness score. The average EAS was $17.7/45 \pm 5.9$, with the highest score of 30 and the lowest score of zero (Figure 1). EAS was a significant association among those with children but not with gender ($p=0.06$), marital status ($p=0.47$), or education level ($p=0.07$) (Table 5). The data show a positive correlation with EAS with monthly income $r=0.10$ ($p=0.02$), and education level $r=0.08$ ($p=0.07$). On the other hand, there is a negative correlation between age and EAS, $r=-0.05$ ($p=0.26$).

Table 5 - Significance of epilepsy awareness score (EAS) with participants' demographics and epilepsy background.

Category	Mean score out of 45±SD	P-value
<i>Gender</i>		0.064
Male	17.27±6.4	
Female	18.24±5.3	
<i>Age Group</i>		0.000*
18-29	18.34±6.3	
30-55	17.08±5.6	
>55	19.40±4.1	
<i>Marital Status</i>		0.472
Single	17.57±5.8	
Married	17.96±6.2	
<i>Do you have Children?</i>		0.038*
Yes	17.36±5.6	
No	18.43±6.0	
<i>Educational Level</i>		0.065
Elementary School	17.00	
Middle School	16.15±6.0	
High School Diploma	16.62±5.7	
Diploma	17.00±5.0	
Bachelor's Degree	18.48±6.1	
Master's Degree	16.38±8.2	
Doctoral Degree	23.00±2.8	
<i>Monthly income</i>		0.003*
<5,000 Saudi Riyal	17.14±5.9	
5,000-10,000 Saudi Riyal	17.80±6.4	
>10,000 Saudi Riyal	18.62±5.4	
<i>Occupation</i>		0.015*
Physician	25.50±2.6	
KAU ^a Rabigh Medical Student	20.96±4.8	
KAU ^a Rabigh Student	15.96±6.4	
High school teacher	17.67±4.7	
Middle school teacher	14.82±4.9	
Elementary school teacher	18.54±6.2	
Freelance	15.69±6.4	
Unemployed	17.83±5.1	
Other	16.92±5.7	
<i>Have you ever read about epilepsy or "convulsive seizures" (fits)?</i>		0.002*
Yes	18.10±5.7	
No	14.08±7.0	
<i>Do you know anyone who has epilepsy?</i>		0.000*
Yes	0±0	
No	18.12±5.8	
I don't know	14.54±6.5	
<i>Have you ever seen anyone having an active seizure?</i>		0.000*
Yes	18.78±5.5	
No	16.61±6.3	
I don't know	14.39±5.6	
<i>Do you know what to do if someone is having a seizure in front of you?</i>		0.000*
Yes	21.05±4.7	
No	16.00±5.9	
I don't know	16.23±5.7	
<i>Have you ever received first aid training regarding the management of epilepsy?</i>		0.000*
Yes	21.09±5.0	
No	16.73±5.9	

* Indicates statistically significant difference

Discussion. Epilepsy patients tend for poor mental health, especially children. Combining with social stigma and lack of social support, the patient will suffer and have a poor quality of life. Therefore, a cornerstone

to improving mental health for epilepsy patients is to have good social support and normalize the stigma of the disease. However, Rabigh is a province growing and transforming into a more urbanized area as many

participants found to be moved from other provinces for work or study, most probably as the students represent almost one-third of the participants. Therefore, the combination of old and young generations may result in ambiguous situations that need investigation for better intervention in the future.⁸ Males and females were almost equally surveyed in this study, with the majority being middle-aged and educated. Most of the participants claim previous reading regarding epilepsy, and half of them witnessed an active seizure. However, only one-third stated to know what to do during an active seizure, and a mere 23% received first aid training for seizure management.; despite the epilepsy awareness campaigns in SA.¹⁴ However, there is not enough information about establishing awareness campaigns in Rabigh. Epilepsy awareness was also lacking in other Arab countries and some African and Asian countries.¹⁵⁻¹⁷ In addition, developed countries such as the United States have reported insufficient public knowledge regarding epilepsy,¹⁸ indicating that epilepsy awareness should be a global concern.

During an active seizure, most participants did not know what actions to take other than moving the seizing person away from harm. Answers such as putting a spoon or cloth in their mouth, splashing water on the person, holding or fixating them, or forcing their medication in their mouth are less than beneficial actions that could potentially be more harmful.¹⁹ Similar data was revealed in Saudi systematic review and meta-analysis study,¹⁴ and studies in other countries,^{20,21} suggesting further education regarding the first aid management of seizures is needed not only among the local population but also in other countries as well.

Participants had adequate knowledge of the symptoms of epilepsy attack, but improvement is needed as many recognize or are unsure if headache or hallucination is one of the symptoms. The causes of epilepsy can be divided into four categories: developmental, acquired, provoked, and cryptogenic epilepsy.²² Participants are mainly were able to identify the various causes of epilepsy correctly. However, the evil eye was mentioned among the causes of epilepsy more than the other common misconceptions causes mentioned in SA society, which is similar to another study in the western region of SA.¹⁰ Those who have previous reading regarding epilepsy, or those who witnessed an active seizure or claim they know what to do to someone having an active seizure or had first aid training all have significantly higher EAS. Therefore, establishing awareness campaigns, increasing first aid training, and improving self-efficacy to handle an active

seizure all positively impact awareness and attitude toward epilepsy patients.

Regarding the stigmatization of the disease, many agreed that epilepsy was highly stigmatized but did not mind if their children socialized with epilepsy patients. Participants were undecided on their reactions if their child would marry a person with epilepsy. One study in Montenegro revealed similar results regarding marriage; however, parents were also anxious about having their children play with those with the disease.²³ Parents of children with epilepsy are aware that their children are stigmatized due to their disease and worry about their offspring's future.²⁴

Studies for teachers' epilepsy awareness are limited in SA.⁷ However, our data show that elementary school teachers have higher EAS than others (Table 5). On the other hand, a recent review study by Alkhotani²⁵ shows that high school teachers had a higher level of awareness. Similar studies revealed that the younger teachers, the better their awareness.^{25,26} Also, our data show that the lower the age, the higher is EAS; however, it is not statistically significant ($p=0.26$).

We cover most of the questions in previous studies regarding epilepsy awareness in SA. However, this study has limitations as some variables have fewer than 5 respondents or are more deficient in one group than the rest, which may be imprecise in some analysis results. In addition, it should be considered that the sample contains a small number of ages over 55. Therefore, age-related results should be interpreted cautiously, and further research should cover older age.

Conclusion. Further efforts are needed to strengthen community knowledge and awareness regarding epilepsy. Stigmatization of the disease in society not only affects those that are afflicted, but it has consequences on their loved ones as well. Supplementary educational campaigns need to be carried out to normalize this condition and create acceptance and increase awareness regarding first aid in the community.

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