

Epilepsy Stigma Among University Students in Makkah: A Cross-Sectional Study

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Background: Epilepsy is a neurological disorder characterized by a persistent propensity to generate recurring epileptic seizures. Young adults such as university students can bridge the gap and improve attitudes toward patients with epilepsy and reduce stigma. This study aims to assess the knowledge and attitude of university students in the city of Makkah about epilepsy.

Methods: This cross-sectional descriptive study was carried out at main universities in the Makkah region of Saudi Arabia. The study was conducted after getting approval from Umm Al-Qura University's ethics and research committee. A total of 394 participants were enrolled in the study, and a stratified random sampling (probability sampling) technique was used to select respondents.

Results: The study included students with a mean age of 20.9 ± 4.6 (18–28 years), 271 (68.8%) students were females, 374 (94.9%) of the students agreed that epilepsy is not contagious, and 215 (54.6%) refused the impact of epilepsy on patients' marital status, relationships and fertility, respectively, 213 (54.1%) of the students reported that they feel scared to witness a seizure. About 334 (84.8%) respondents believed that epilepsy is an affliction, and 123 (31.2%) reported that they thought epilepsy was a supernatural phenomenon or black magic.

Conclusion: The study concluded a satisfactory level of awareness among university students in Makkah related to dealing with patients with epilepsy. Further scientific studies will help build student's positive attitudes through simulation programs and interventional studies.

Keywords: people with epilepsy, stigma, epileptic seizures, Saudi community, neurological disorder

Introduction

Epilepsy is a neurological disorder characterized by a persistent propensity to generate recurring epileptic seizures. The "International League against Epilepsy – ILAE" explained epilepsy with the presence of 1) at least two reflex or unprovoked seizures within the period of >24 hours apart or 2) probability of further seizures and one unprovoked seizure with a general reoccurrence risk of 60%, after two reflex seizures, occurring over next ten years or 3) epileptic syndrome diagnosis.^{1,2} Around 65 million live with epilepsy globally, with a pooled incidence rate of 61.4 every 100,000 people per year, out of which 4.7 million people with epilepsy are from Middle East countries.^{3,4} The studies suggest higher epilepsy incidence in lower-middle-income countries 139.0 (95% CI 69.4–278.2) in comparison to high-income countries 48.9 (95% CI 39.0–61.1).⁵ The estimated prevalence of epilepsy in Saudi Arabia (KSA) is 6.54 every 1000 persons. The cumulative prevalence of medically resistant epilepsy (MRE) in KSA is 30%.^{6,7} Similarly, the prevalence of epilepsy is highest in adolescence and early childhood. The estimated prevalence for age 10–19 is 8.86 (95% CI (6.58–11.92) and for age 20–29 is 9.14 (95% CI (7.17–11.64)).⁸

In some places, epilepsy is regarded to be linked to mental reasons; in others, supernatural beliefs and epilepsy are thought to be linked. Epilepsy patients confront several challenges. Recurrent seizures,⁹ or the etiology of epilepsy,² drug adverse effects,¹⁰ and major psychosocial and neurocognitive issues¹¹ are all part of it. This has a significant influence on people with epilepsy (PWE). That belief and misconception of epilepsy resulted in the mistreatment of epilepsy patients. Across several nations, PWE suffered from different degrees of stigmatization and PWE isolation. Several studies have

shown stigmatization and poor knowledge about epilepsy. Over the years, public knowledge about epilepsy has improved in several countries. Still, it remained a significant problem in others. In KSA, studies showed improvements in knowledge across the years, but despite the health education toward improving knowledge about epilepsy, there are still gaps in knowledge and attitude.^{12–14}

For generations, in the Saudi community, an association between spirits possession and stigmatization of epileptic patients is believed.¹⁵ Young adults, such as university students, can bridge the gap, improve PWE attitudes, and reduce stigma. Young adults are a potentially vital source to change the public attitude toward epilepsy patients. They can affect the younger generation and spread the correct information among older generations. This study aims to assess the knowledge and attitude of university students in the city of Makkah about epilepsy.

Materials and Methods

This cross-sectional descriptive study was carried out at the main universities in the Makkah region of Saudi Arabia from November 2021 till January 2022. The study was conducted after approval from Umm Al-Qura University's ethics and research committee (Approval No. HAPO-02-K-012-2021-11-84). A total of 394 participants were enrolled in the study. A stratified random sampling (probability sampling) technique selected respondents. The sample size was calculated using the "Raosoft" calculator with a 5% margin of error, 95% confidence level, and 50% response distribution.

The study included respondents enrolled in universities only in the Makkah region, able to understand Arabic and English, above 18 years of age, and willing to participate in the study. Students with epilepsy history and incomplete responses to the questionnaire were excluded from the study. The study utilized an electronic self-administered questionnaire adapted and modified from previous studies with a cover letter stating the study objective. The respondents willing to participate in the study filled out the informed consent and agreed to the study objective before filling out the questionnaire. The questionnaire was distributed electronically among university students in the Makkah region. Two independent researchers (A) and (B) reviewed the questionnaire, and the participant's identity was kept confidential.

The questionnaire consisted of 30 questions, divided into three sections, including participant's demographic details (age, gender, year of study, type of college, etc), knowledge about epilepsy, and stigma-related questions. The questionnaire used a (Yes/No/Do not Know) and (Agree/Disagree/Do not Know) nominal scale. For knowledge and perceived awareness items, each correct answer was scored one point, and the total summation of the discrete scores of the different items was calculated. A participant with a score less than 60% (0–12 points) of the total score was considered poor awareness, while good awareness was considered if he had a score of 60% (13 points or more) of the total or more.

Statistical Analysis

After data were extracted, it was revised, coded, and fed to statistical software IBM SPSS version 22.0 (SPSS, Inc. Chicago, IL). All statistical analysis was done using two-tailed tests. A P-value less than 0.05 was considered statistically significant. Descriptive analysis based on the frequency and percent distribution was done for all variables, including students' socio-demographic data, study grade, family and personal history of epilepsy, and source of information regarding epilepsy. Also, participants' knowledge and perceived awareness regarding epilepsy and their stigma and attitude towards epilepsy patients were shown in frequency tables. Cross tabulation was used to assess the distribution of students' knowledge level and awareness regarding epilepsy according to their data, family history, and source of information. Relations were tested using the Pearson chi-square test and exact probability test for small frequency distributions.

Results

A total of 394 university students completed the study questionnaire. [Table 1](#) demonstrates the participant's demographic details. The study included students with a mean age of 20.9 ± 4.6 with a female preponderance ($n=271$, 68.8%). The majority of the students ($n=235$, 59.6%), were in their intermediate years followed by 100 (25.4%) were in their graduation year, and 47 (11.9%) were in their preparatory year. Considering student type of colleges, 189 (48%) participants were enrolled at the college of medicine, 88 (22.3%) at scientific colleges, 68 (17.3%) at social colleges,

Table 1 Socio-Demographic Data of Enrolled Participants (University Students) in Makkah, Saudi Arabia

Socio-Demographic Data	No.	%
Age in years		
<20	72	18.3
20–22	214	54.3
22–24	67	17.0
>24	41	10.4
Gender		
Male	123	31.2
Female	271	68.8
Study grade		
Preparatory year	47	11.9
Post preparatory year	235	59.6
Graduation year	100	25.4
Diploma	12	3.0
College nature		
Medical	189	48.0
Scientific	88	22.3
Social	68	17.3
Religious	49	12.4
Heard about epilepsy		
Yes	381	96.7
No	13	3.3
Do you have a relative with epilepsy/ convulsions		
Yes	130	33.0
No	264	67.0

and 49 (12.4%) at religious colleges. Three hundred and eighty-one (96.7%) students heard about epilepsy, while 130 (33%) had a family relative with epilepsy.

The study also evaluated the knowledge and perception of university students regarding epilepsy in Makkah, Saudi Arabia (Table 2). The results showed 326 (82.7%) students were aware of epilepsy as a neurological disorder, and 219 (55.6%) agreed that it is not a psychological disorder. In total, 338 (85.8%) of the students decided that children with epilepsy can play with other children. However, 331 (84%) participants believed that epilepsy could affect patients driving. On the other hand, 374 (94.9%) of the students agreed that epilepsy is not contagious, and 215 (54.6%) refused the impact of epilepsy on patients' marital status, relationships and fertility, respectively. In total, 194 (49.2%) respondents refused epilepsy impact on patients' daily physical activities like sports, and 153 (38.8%) did not believe in any difference in epileptic patients treatment from other regular patients. Regarding perceived awareness, 356 (90.4%) of the study students disagreed that patients with epilepsy are aggressive and abusive, 271 (68.8%) opposed to the patient with epilepsy is contagious or genetic, which may affect his relationships, 240 (60.9%) participants refused that patient with epilepsy may cause discomfort to the people around him, and 189 (48%) refused that patient with epilepsy suffer from personality disorders more than others. Additionally, 316 (80.2%) agreed that epileptic patients could live as normal as others.

The university students' stigma, attitude and belief towards epilepsy patients in Makkah, Saudi Arabia, was studied and demonstrated in Table 3. In total, 213 (54.1%) of the students reported that they feel scared to witness a seizure. About 334 (84.8%) respondents believed that epilepsy is an affliction, and 123 (31.2%) reported that they think of

Table 2 University Students' Knowledge and Perception Regarding Epilepsy in Makkah, Saudi Arabia

Knowledge Items	Yes		No		Do Not Know	
	No.	%	No.	%	No.	%
Is epilepsy a neurological disease?	326	82.7	10	2.5	58	14.7
Is epilepsy a mental illness?	72	18.3	219	55.6	103	26.1
Is epilepsy a genetic disease?	129	32.7	96	24.4	169	42.9
Is epilepsy contagious?	5	1.3	374	94.9	15	3.8
Do you think that epilepsy patients are treated differently from others?	175	44.4%	153	38.8	66	16.8
Epilepsy affects patient occupation	259	65.7	102	25.9	33	8.4
Epilepsy affects patients in military force	315	79.9	37	9.4	42	10.7
Epilepsy affects patients' marital status, relationships and fertility	118	29.9	215	54.6	61	15.5
Epilepsy affects patients driving	331	84.0	39	9.9	24	6.1
Epilepsy affects patients' daily activities like sports	132	33.5	194	49.2	68	17.3
A child with epilepsy can play with other children	338	85.8	12	3.0	44	11.2
Perceived Awareness	Agree		Disagree		Do Not Know	
	No.	%	No.	%	No.	%
Patients with epilepsy may cause accidents at work, at home or on the road	283	71.8	45	11.4	66	16.8
Patients with epilepsy may miss work frequently	93	23.6	194	49.2	107	27.2
Patients with epilepsy may cost insurance companies	69	17.5	168	42.6	157	39.8
Patients with epilepsy are aggressive and abusive	9	2.3	356	90.4	29	7.4
Patients with epilepsy may cause discomfort to the people around them	57	14.5	240	60.9	97	24.6%
Patient with epilepsy is contagious or genetic, which may affect his relationships	37	9.4	271	68.8	86	21.8
Patients with epilepsy have normal intelligent	285	72.3	25	6.3	84	21.3%
Patients with epilepsy can succeed personally and professionally	341	86.5	16	4.1	37	9.4
Patient with epilepsy suffers from personality disorders more than others	67	17.0	189	48.0	138	35.0
Patients with epilepsy can live as normal as others	316	80.2	29	7.4	49	12.4

epilepsy as a supernatural phenomenon or black magic. The majority of the students (85.8%) disagreed with epilepsy as a punishment for the patient, and 254 (64.5%) agreed as an employer to hire someone with epilepsy. Moreover, 156 (39.6%) accepted to marry a person with epilepsy, and 276 (70.1%) believed in religious treatment for epilepsy, such as ruqyah along with medical treatment, while only 42 (10.7%) believed totally in spiritual therapy for epilepsy. Also, 194 (49.2%) believed in herbal medicine and alternative treatment for epilepsy like walking on sand for better recovery from epilepsy.

Figure 1 demonstrates university students' knowledge and perception regarding epilepsy, Makkah, Saudi Arabia. A total of 200 students (50.8%) had a good knowledge level and perception regarding epilepsy patients, and 194 (49.2%) had poor knowledge and perception level.

Figure 2 presents the relationship between the source of university students' knowledge and perception regarding epilepsy in Makkah, Saudi Arabia. The results showed that study was the most reported source of knowledge (32%), followed by TV and internet (20.6%), community (18.5%), relative patient (16.2%) while physicians were reported by 6.1% of the students, respectively.

Table 4 demonstrates the association between university students' knowledge level and perception regarding epilepsy by their socio-demographic data. A statistically significant difference was observed between different study grade students (P -value: 0.025). Similarly, a statistically significant difference (P -value: 0.049) was reported among students

Table 3 University Students' Stigma, Attitudes and Beliefs Towards Epilepsy Patients, Makkah, Saudi Arabia

Stigma, Attitudes and Beliefs Towards Epilepsy Patients	No	%
It is scary to witness a seizure.		
Yes	213	54.
No	145	36.8%
Do not know	36	9.1
If you are an employer, do you hire someone with epilepsy?		
Yes	254	64.5
No	26	6.6
Do not know	114	28.9
Do you accept to marry a patient with epilepsy?		
Yes	156	39.6
No	111	28.2
Do not know	127	32.2
Do you believe epilepsy is an affliction?		
Yes	334	84.8
No	29	7.4
Do not know	31	7.9
Do you believe epilepsy is a punishment for the patient?		
Yes	8	2.0
No	338	85.8
Do not know	48	12.2
Do you think epilepsy is a supernatural phenomenon or black magic?		
Yes	123	31.2
No	159	40.4
Do not know	112	28.4
Do you believe in religious treatment for epilepsy, such as ruqyah and others?		
Yes, totally	42	10.7
Yes, with medical treatment	276	70.1
No	76	19.3
Do you believe in herbal medicine and alternative therapy for epilepsy like walking on sand and other?		
Yes, totally	23	5.8
Yes, with medical treatment	194	49.2
No	177	44.9

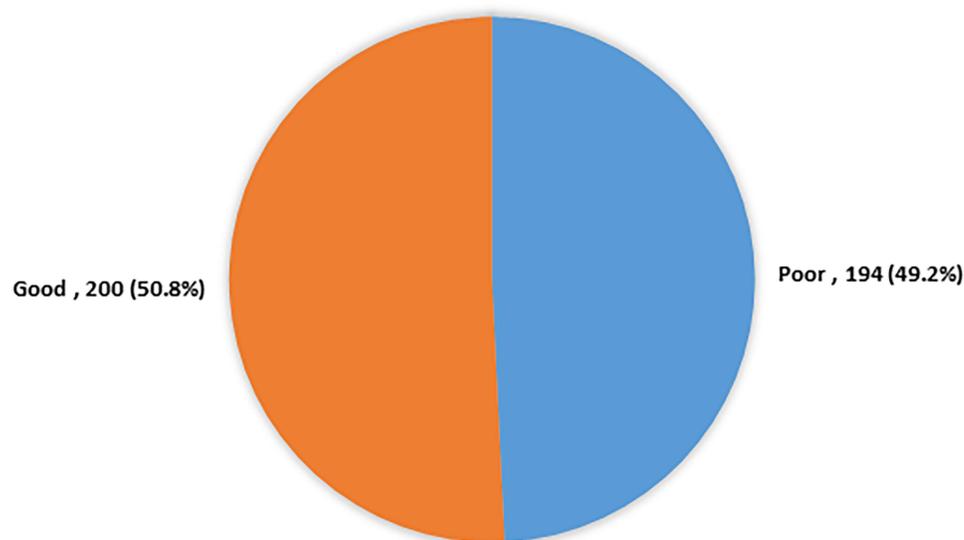


Figure 1 Overall university students' knowledge and perception regarding epilepsy, Makkah, Saudi Arabia.

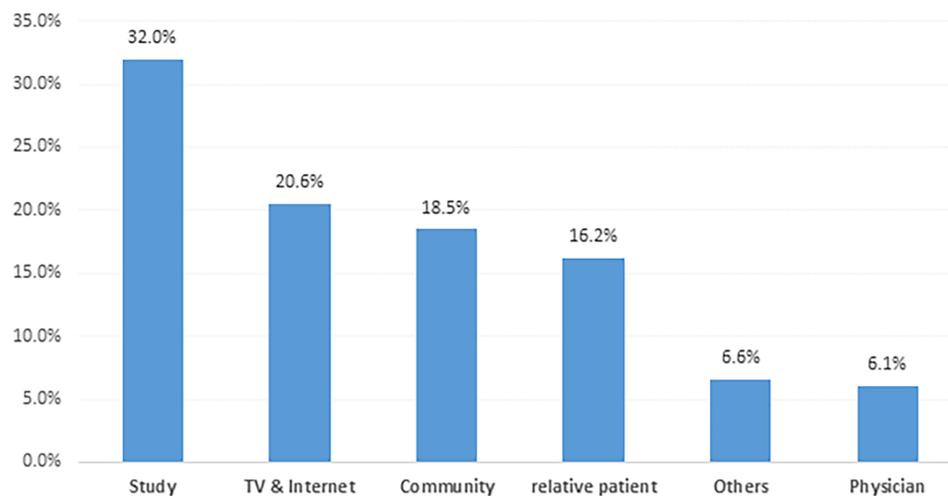


Figure 2 Source of university students' knowledge and perception regarding epilepsy, Makkah, Saudi Arabia.

studying in medical colleges (57.1%) in comparison to social (48.5%), religious (44.9%), and scientific colleges (42%), respectively.

Discussion

The study looked at the stigma associated with epilepsy among university students in Makkah. The findings revealed that 54.3% were between the ages of 20 and 22, with a mean age of 20.9 ± 4.6 (18–28 years) and that the majority of respondents were female (68.8%) and male (31.2%), respectively. In contrast, research done in Qassim, Saudi Arabia, found that males (59.3%) were more likely to participate than females (40.6%), with 59.7% of respondents aged 15–30 years.¹⁶ Forty-eight percent of our research was from medical universities. Shihata et al⁶ did another research among medical students at King Abdul-Aziz University in Jeddah. It revealed students' misconceptions about the causes of epilepsy, treatment options, and attitudes toward epileptic patients. Hakami et al¹⁵ also found that health colleges had a superior understanding of how to distinguish epilepsy from other illnesses. Medical students also know about epilepsy

Table 4 University Students' Knowledge Level and Perception Regarding Epilepsy by Their Socio-Demographic Data

Socio-Demographic Data	Knowledge Level				p-value
	Poor (0–12)		Good (13–21)		
	No.	%	No.	%	
Age in years					0.081
<20	41	56.9	31	43.1	
20–22	108	50.5	106	49.5	
22–24	24	35.8	43	64.2	
>24	21	51.2	20	48.8	
Gender					0.237
Male	66	53.7	57	46.3	
Female	128	47.2	143	52.8	
Study grade					0.025*
Preparatory year	30	63.8	17	36.2	
Post preparatory year	120	51.1	115	48.9	
Graduation year	38	38.0	62	62.0	
Diploma	6	50.0	6	50.0	
College nature					0.049*
Medical	81	42.9	108	57.1	
Scientific	51	58.0	37	42.0	
Social	35	51.5	33	48.5	
Religious	27	55.1	22	44.9	
Heard about epilepsy?					0.042* [§]
Yes	184	48.3	197	51.7%	
No	10	76.	3	23.1%	
Do you have a relative with epilepsy/ convulsions?					0.198
Yes	58	44.6%	72	55.4	
No	136	51.5	128	48.5	
Source of information					0.159 [§]
Physician	10	41.7	14	58.3	
TV and Internet	50	61.7	31	38.3	
Study	54	42.9	72	57.1	
Community	35	47.9	38	52.1	
Relative patient	31	48.4	33	51.6	
Others	14	53.8	12	46.2	

Note: [§]Exact probability test. *P< 0.05 (significant).

Abbreviation: P, Pearson χ^2 test.

as a medical illness, according to Alsaab et al.¹⁷ Results showed 86.8% of the students were positively able to distinguish seizure as abnormal electrical discharge in the brain.

In our study, we assessed the knowledge and perceptions of university students in Makkah, Saudi Arabia, about epilepsy. The results showed that 374 (94.9%) of the students agreed that epilepsy is not contagious, and 215 (54.6%) of the students denied the impact of epilepsy on patients' marital status, relationships, and fertility. In a survey done by Ghaffar et al.¹⁸ in the Aseer region of Saudi Arabia, 95.8% of the participants disputed that epilepsy is a contagious illness. The population's knowledge regarding epilepsy improved in KSA in the past few years as the percentage of believers in epilepsy as contagious decreased in different regions decreased relatively.^{14,17,19,20} PWE marital chances were researched by Almarzouqi et al.,²³ who found that socio-demographic characteristics, such as employment, had

a substantial impact on PWE matrimonial prospects. Similarly, PWE's social history adds to the stigma that surrounds patients, resulting in a negative attitude toward PWE in social relationships, employment, and education. As a result, social support can help with non-clinical problems about PWE.²⁴ In our study, 18.3% of the people thought epilepsy was a mental condition, 82.7% thought it was a neurological problem, and 32.7% thought it was a hereditary issue. Another research²⁴ found that 17.1% of the people thought epilepsy was caused by a hereditary issue, and 60% thought it was caused by brain illnesses. Epilepsy problems and accompanying seizures can have a social impact and stigmatize PWEs in a variety of ways. According to our research, 64.5% of university students in Makkah would hire PWE if given the opportunity. This conclusion is in line with the findings of other studies.^{18,21,22} Approximately 334 (84.8%) respondents believe epilepsy is a disease, while 123 (31.2%) believe epilepsy is a supernatural phenomenon or black magic, indicating a negative attitude toward epilepsy, implying that despite public awareness efforts and modern education, a negative perception of PWE still exists in Saudi Arabia. This situation also exists in other Middle Eastern nations, such as the United Arab Emirates²⁵ and Iran.²⁶ Another research performed among university students in Kuwait²⁷ found that a quarter of the participants believe in bad spirits as the cause of epilepsy, which is five times greater than the Malaysian study.²⁸ Discrimination against PWE in educational institutions and the workplace deprives participants of their right to equal opportunity.

These abuses of social and civic rights were visible in emerging nations. However, 64.5% of the students agreed to hire PWE in the workplace in our survey. Research in Saudi Arabia¹⁵ found a strong link between university students' degree of knowledge and the reduction of stigma among diverse professions ($P < 0.001$) and encouraged epileptic patients to consult with healthcare specialists. Overall, our research revealed that university students in Makkah had a good attitude regarding coping with PWE. The study's weakness was the limited exposure and understanding of certain students when filling out the questionnaire. Every year, the Saudi Epilepsy Society Chapter holds educational events in the community to raise awareness of the problems, insecurities, and stigma associated with epilepsy, as well as to provide training in the first aid care of PWE and seizures.¹ However, further research at the university level is needed to eliminate societal stigma, raise epileptic patient awareness, and improve quality of life in PWE.

Conclusion

This study concluded that university students in Makkah have a satisfactory level of awareness related to epilepsy. The present study found that graduation year students had a good knowledge level. However, there is still a requirement to improve knowledge and attitude toward PWE to reduce the stigma and misconceptions associated with epilepsy among the population in Makkah through intervention programs. This can be attained by incorporating further training and educational awareness programs at the higher education level in universities about the nature of the disease and its treatment, along with the overall social role of the community. Through simulation programs and interventional studies, further scientific studies will help build students' positive attitudes among youth and adults.

Abbreviations

KSA, Kingdom of Saudi Arabia; MRE, medically resistant epilepsy; ILAE, International League against Epilepsy; PWE, people with epilepsy.

Data Sharing Statement

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Ethics Approval

This study was approved by the Umm Al-Qura University's ethics and research committee. This study adhered to the principles of the Declaration of Helsinki.

Consent for Publication

Participants were informed that their participation is anonymous and their responses are confidential.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

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