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Public awareness, knowledge, and attitudes regarding epilepsy in the Qassim region, Saudi Arabia

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ABSTRACT

Introduction: Epilepsy is a chronic condition and has significant negative consequences to quality of life. Misconceptions regarding epilepsy among communities with lower rates of education have led to false beliefs and ideas. This study aimed to evaluate the awareness, knowledge, and attitudes about epilepsy in Saudi population at Qassim region, Saudi Arabia.

Methods: A cross-sectional study was conducted using a previously validated 14-item questionnaire. The data were collected online via WhatsApp application. The Saudi adult population (18 years and older) within Qassim region was sampled for the present study.

Results: A total of 403 respondents completed the survey and the majority (68.8%) were less than 30 years old. Nearly all participants (97.0%) had heard of epilepsy or convulsive seizures; 43.5% knew a person with the disease; and 48.4% had seen a person having a seizure. Participants cited brain disorders (68.1%) as the most common cause of epilepsy, followed by mental disorders (61.9%) then hereditary diseases (48.8%). Only 5.6% would protest against their children associating with a person who occasionally experiences seizures, and a similarly small percentage (7.9%) would do so if their son or daughter decided to marry such a person.

Conclusion: The public's general attitudes and awareness of epilepsy were quite good; however, knowledge regarding this medical condition is still inadequate. Thus, more campaigns are needed in order to increase societal awareness on epilepsy, obtaining help from governmental agencies, health institutions, mass media, and other health-related organizations.

1. Introduction

The World Health Organization (WHO) defines epilepsy as a chronic neurological disorder that affects millions worldwide. Specifically, approximately 50 million people are affected annually [1]. In Arab countries, the prevalence of epilepsy ranges from 0.9/1000 in Sudan and 6.5/1000 in Saudi Arabia. Furthermore, the total number of people diagnosed as having epilepsy was estimated to have reached 724,500. Children have higher prevalence in this countries compare with adult [2]. Negative perception and lack of knowledge about epilepsy in Arab population were documented in different studies. Arab culture is playing an important role in epilepsy misconceptions as most of the families seek treatment from faith healer. Additionally, most of the Arabs believed that devils or spirits are the causes of epilepsy [3].

Quality of life among people with epilepsy is not ideal. Additionally, people with epilepsy experience many forms of discrimination, which can negatively affect their way of life [4]. Misconceptions regarding epilepsy among communities that are less educated, and have inadequate treatment options, might generate false beliefs, which could lead to further difficulties among individuals affected by this disorder [5]. Several studies have shown that prenatal and perinatal conditions are the most crucial risk factors for epilepsy, thus explicating an important role of prevention [5,6]. Prevention is accomplished by raising awareness among communities and healthcare providers [7]. A 30-year study in the US revealed a trend toward increased epilepsy awareness in recent years [8]. Furthermore, quality of life and public acceptance of individuals with epileptic disorders tend to be higher in Western as compared with Middle Eastern countries. This is also the case among highly educated, relative to less educated communities [5,9,10]. In Saudi Arabia, there is some improvement in knowledge and awareness about epilepsy although some Saudi people linked it to evil and spirits [11].

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Therefore, the present study aimed to determine familiarity with, knowledge of, misunderstandings about, and attitudes toward epilepsy among residents from the Qassim region of Saudi Arabia. Importantly, we examined how respondents' sociodemographic characteristics influenced their familiarity, knowledge, misunderstandings, and attitudes toward epilepsy. The present findings have the potential to provide a more thorough understanding regarding the quantification of false beliefs concerning epilepsy within a Middle Eastern context, which is essential before implementing public epilepsy education.

2. Method

A cross-sectional study was conducted using a previously validated 14-item questionnaire designed to survey public awareness, knowledge, and attitudes about epilepsy. The questionnaire was hosted by Google form and sent through WhatsApp messenger application. The questionnaire was distributed through 20 volunteers living in different cities in Qassim region and sent to all their contacts. Objectives of the study were explained to participant, and informed consent in Arabic language was taken before proceeding to answer the questions. Potential participants needed to be over the age of 18 without any personal or family history of diagnosed epilepsy. The estimated population of the Qassim region is more than one million, of whom 80.4% are Saudis and 19.6% are non-Saudis. Buraidah is a city and the capital of Al-Qassim region with a population of 845,505 and about 50% of the total population of the region.

For a proportion of 0.05 among a target population with definite characteristics, a Z-statistical value of 1.96, and significance at a 0.05 level, the required sample size was 384 using n = z2pq\d2. We rounded up our ideal sample size to 400; however, to guarantee accuracy, the sample size was increased to 403 to account for data loss and nonresponse rates. A validated and translated questionnaire was obtained from a study conducted in the Asser region of Saudi Arabia [12]. The study objectives were explained to each participant by stressing the importance of the data and its confidentiality. Consent to participate was received before administering the online questionnaire. The Qassim Ethical Committee approved this protocol. Data were placed in a password-protected device with primary investigator and coinvestigator, and confidentiality of all data was ensured.

All questionnaire data were extracted into an excel worksheet for translation and then exported into SPSS (version 20) for further tabulation and subsequent statistical analyses. Both descriptive and inferential statistics were calculated with numbers and percentages. A p-value of 0.05 (95% confidence interval [CI]) was used to determine statistical significance. To evaluate predictors for the outcome variable, all continuous variables deemed as nonparametric so we used Mann–Whitney *U* test or the Kruskal–Wallis test to determine their significance. Normality, statistical interactions, and collinearity (i.e., variance inflation factor) were also assessed with the Kolmogorov–Smirnov and Shapiro–Wilk test.

Public awareness regarding epilepsy comprised 3 questions with a "Yes" response coded as 2, "No" coded as 1, and "I don't know" coded as 0; a total score was calculated by adding the scores on all 3 questions. The minimum score was 0, and the maximum was 6, with a mean score = 4.7 (standard deviation [SD] = 1.0) in the present sample. High scores (4–6) were classified as "good" awareness, while low scores (0–3) were classified as "poor" awareness.

Public attitudes toward epilepsy comprised 5 questions with a "Yes" response coded as 2, "No" coded as 1, and "I don't know" coded as 0; a total score was calculated by adding the scores on all 5 questions. The minimum score was 0, and the maximum was 10, while the mean score = 7.6 (SD = 2.2) in the present sample. Scores between 0 and 5 were classified as a "negative" attitude, while scores between 6 and 10 were classified as a "positive" attitude.

Public knowledge regarding epilepsy comprised 4 questions with a "Yes" response coded as 2, "No" coded as 1, and "I don't know" coded as 0; a total score was calculated by adding the scores on all 4 questions. The minimum score was 0, and the maximum was 8, while the mean score = 5.2 (SD = 1.2) in the present sample. Scores between 0 and 4 were classified as "poor" knowledge, and scores between 5 and 8 were classified as "good" knowledge.

3. Results

A total of 403 respondents were recruited for the present study (Table 1). Females dominated the males (59.8% vs 40.2%) where majority aged less than 30 years old (68.8%). Most participants were living at Buraidah (61.6%) with more than a half were not married (59.3%). Many of them were educated (77.2%), however, unemployed are high (68.1%).

Nearly all participants (97.0%) had heard about epilepsy or convulsive seizures; 43.5% knew a person with the disease; and 48.4% had seen a person having a seizure (Table 2). Only 5.6% would protest against their children associating with a person who occasionally experiences seizures, and a similarly small percentage (7.9%) would do so if their son or daughter decided to marry such a person. Most participants agreed that people with epilepsy should not be barred from engaging in a job, and a high percentage (84.9%) believed that a child with epilepsy could be successful in a class with healthy children. A relatively small portion (7 participants) believed that epilepsy was a form of insanity. The most common actions to be performed when someone is having a seizure were keep him/her away from danger (92.8%), followed by put a piece of cloth or spoon in his/her mouth (45.3%), and the least action was to force him/her to take his/her medication (12.6%) while the most common methods that should be suggested for people with epilepsy were to seek medical advice (96.5%), or no need to seek further treatment (82.1%) whereas the least suggestion was the use of acupuncture (7.2%).

Fig. 1 depicts the reported causes of epilepsy. Brain disorder was rated as the highest (68.1%), followed by mental disorder (61.9%), and hereditary disease (48.8%); a relatively low percentage cited a blood disorder (12.3%), birth defect (15.1%), and a contagious disease (1.4%) as causes.

The distribution of participants' reports of epilepsy symptoms is depicted in Fig. 2. Convulsions or shaking was rated the highest (96%); loss of consciousness was rated by 82.1%, while changes in behavior was rated by 46.7% and amnesia by 37.9%.

Table 1
Description of sociodemographic variables.

	N (%) (n = 403)
Gender	
• Men	173 (40.2%)
• Women	257 (59.8%)
Age group in years	
• <30	296 (68.8%)
• 30–39	70 (16.3%)
• ≥40	64 (14.9%)
Area of residence	
• Buraidah	265 (61.6%)
• Al Badaya	58 (13.5%)
• Unaizah	31 (7.2%)
• Al Rass	37 (8.6%)
• Al Bukairiyah	13 (3.0%)
• Others	26 (6.0%)
Marital status	
• Unmarried	255 (59.3%)
• Married	175 (40.7%)
Education level	
• Secondary or lower	98 (22.8%)
• University or higher	332 (77.2%)
Occupation	
• Employed	137 (31.9%)
• Unemployed	293 (68.1%)

Table 2
Awareness, knowledge, and attitudes regarding epilepsy (n = 403).

Statement	Yes N (%)	No N (%)	I don't know N (%)
Awareness			
Q1. Have you ever heard of or read about the disease called "epilepsy" or "convulsive seizures" (fits)?	417 (97.0%)	13 (3.0%)	0
Q2. Do you know anyone who has epilepsy?	187 (43.5%)	196 (45.6%)	47 (10.9%)
Q3. Have you ever seen anyone who was having a seizure?	208 (48.4%)	207 (48.1%)	15 (3.5%)
Attitude			
Q1. Would you object to having any of your children in school associate with persons who sometimes have seizures (fits)?	24 (5.6%)	351 (81.6%)	55 (12.8%)
Q2. Would you object to having any of your children play with persons who sometimes have seizures (fits)?	34 (7.9%)	354 (82.3%)	42 (9.8%)
Q3. Would you object to having a son or daughter of yours marry a person who sometimes has seizures (fits)?	194 (45.1%)	108 (25.1%)	128 (29.8%)
Q4. Do you think people with epilepsy should be employed in jobs like other people?	311 (72.3%)	24 (5.6%)	95 (22.1%)
Q5. Can a child with epilepsy be successful in a class with healthy children?	365 (84.9%)	6 (1.4%)	59 (13.7%)
Knowledge			
Q1. Do you think epilepsy is a form of insanity?	7 (1.6%)	381 (88.6%)	42 (9.8%)
Q2. On seeing someone having a seizure, should you[a]			
• Keep him/her away from danger	399 (92.8%)	5 (1.2%)	26 (6.0%)
• Put a piece of cloth or spoon in his/her mouth	195 (45.3%)	106 (24.7%)	129 (30.0%)
• Restrict/fix him/her to the ground	159 (37.0%)	133 (30.9%)	138 (32.1%)
• Spray water on his/her face	149 (34.7%)	148 (34.4%)	133 (30.9%)
• Force him/her to take his/her medication	54 (12.6%)	225 (52.3%)	151 (35.1%)
Q3. Suggestions for friends or relatives with epilepsy[a]			
• Medical advice	415 (96.5%)	3 (0.7%)	12 (2.8%)
• Indicate that there is no need for treatment	353 (82.1%)	15 (3.5%)	62 (14.4%)
• Indicate that epilepsy is untreatable	256 (59.5%)	32 (7.4%)	142 (33.0%)
• Consult a spiritual healer	136 (31.6%)	212 (49.3%)	82 (19.1%)
• Get medicine from a drugstore	87 (20.2%)	260 (60.5%)	83 (19.3%)
• Use herbal medicine	37 (8.6%)	253 (58.8%)	140 (32.6%)
• Use acupuncture	31 (7.2%)	214 (49.8%)	185 (43.0%)
Q4. Is there a role for surgical intervention in addressing an advanced epileptic attack?	69 (16.0%)	85 (19.8%)	276 (64.2%)

[a] Variable with multiple responses.

The correlation between sociodemographic variables and participants' knowledge, awareness, and attitudes about epilepsy was conducted at Table 3. Based on the results, there was a significant gender difference in awareness ($p = 0.029$) but not in attitudes ($p = 0.153$) or knowledge ($p = 0.090$). Awareness ($p = 0.003$) differed by age group, but this was not the case for attitudes ($p = 0.369$) or knowledge ($p = 0.273$). Awareness ($p = 0.125$), attitudes ($p = 0.373$), and knowledge ($p = 0.615$) did not differ as a function of residence. Awareness ($p = 0.033$) differed based on marital status, but no differences emerged for attitudes ($p = 0.536$) or knowledge ($p = 0.145$). There were no significant differences in awareness ($p = 0.277$), attitudes ($p = 0.187$), or knowledge ($p = 0.148$) as a function of education level. Finally, awareness ($p = 0.003$) and knowledge ($p = 0.043$) differed based on occupational status; this was not the case for attitudes ($p = 0.681$).

4. Discussion

Epilepsy is a chronic disease, with patients frequently experiencing seizures that affect their social life and interfere with daily activities. Prior notions that epilepsy is a form of mental illness are common misconceptions [10]. Because of lack of knowledge, attitudes, and awareness regarding the etiology of this condition, the general public is inclined to disengage from people with epilepsy. The present study provides further understanding regarding public epilepsy knowledge, awareness, and attitudes. Results revealed that nearly all participants (97.0%) had heard of epilepsy or convulsive seizures, while 43.5% knew a person with disease, and 48.4% had witnessed someone having a seizure. These findings are consistent with those from several studies published in Saudi Arabia [12–15]. For instance, Muthaffar and Jan reported that 77.4% of respondents had prior knowledge of epilepsy,

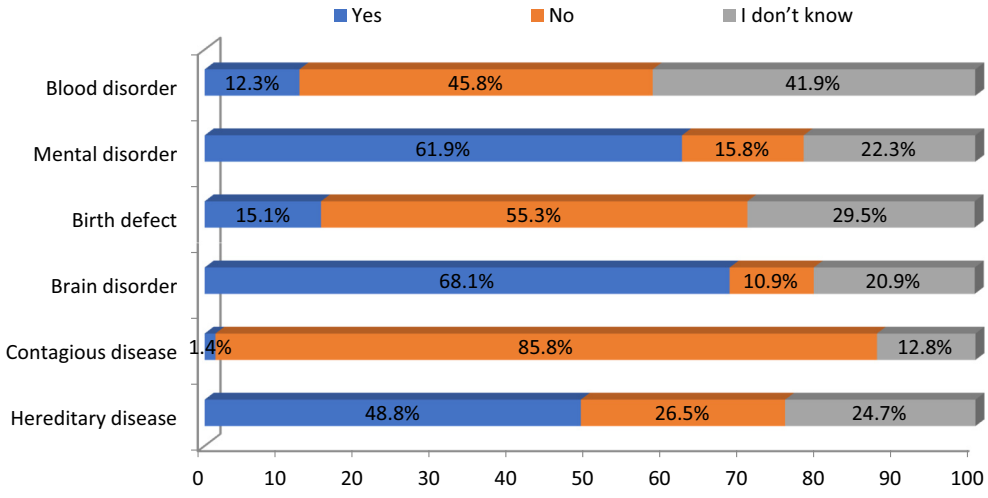

Fig. 1. Distribution of reported causes of epilepsy.

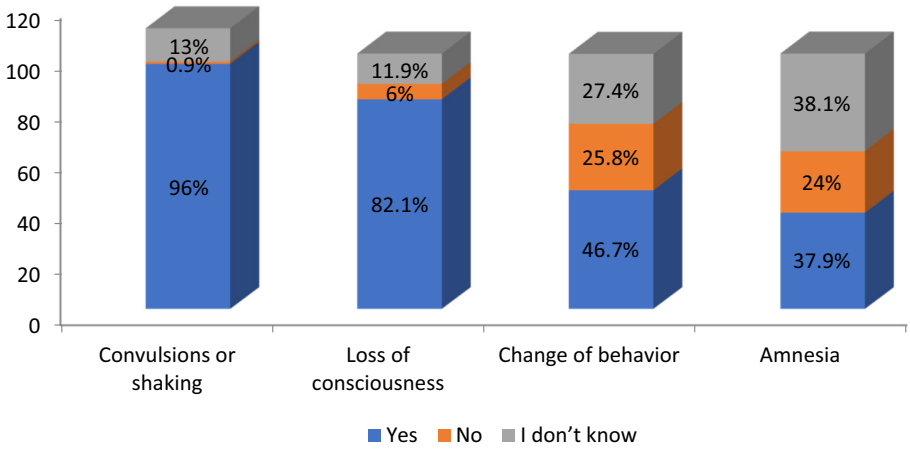

Fig. 2. Distribution of reported symptoms of epilepsy.

50% had observed a person experiencing an epileptic seizure, and 48% knew someone with the disease [11]. Alhazzani et al. reported that 96.1% of Aseer residents had heard about the disease, most knew someone with epilepsy, and 59.1% had witnessed a seizure [12]. Conversely, Alzubaidi and colleagues reported that while all respondents had heard about epilepsy, most had a poor understanding regarding the idiopathic meaning of the disease [13]. This in line with results from Almutairi et al., indicating that 81.4% of respondents had prior epilepsy knowledge, half knew someone with epilepsy, and around 55% had experienced what they believed to be a seizure [14]. The present results are slightly discrepant from one study in Iran, whereby 76.6% of respondents were aware of epilepsy, 23.9% had relatives with epilepsy, and a slightly higher proportion knew someone else with epilepsy (58.1%) [15]. Moreover, in Malaysia, students had different views on the subject, as they exhibited slightly less knowledge about epilepsy (69%) in comparison with the present study [16]. In Brazil, 88.8% of respondents reported knowledge regarding epilepsy, 67% knew someone with epilepsy, and about 60% had witnessed someone having a seizure [17].

In terms of attitudes, only 7.9% of respondents in the present study reported they would protest against their children associating or playing with a person who had epilepsy which is much less than other previous studies done in Majmaah showed (49%) and in Riyadh (27%) wherein they do not allow their children to play with a child with epilepsy [13,15]. Our respondent (45.1%) reported that they would not protest against their children marrying a person with epilepsy, while in both Jeddah (49%) and Majmaah (47.3%), people are not willing to marry a person with epilepsy showing that people in Qassim region are more accepting and with better attitude [13,14].

Many agreed that people with epilepsy should not be prevented from working, while 84.9% agreed that a child with epilepsy could be successful in the classroom, just like any other healthy child which reflecting a good attitude in this community. Similar views have been observed in other studies throughout Saudi Arabia [12–14]. Our findings are also consistent with Iranian study, which demonstrated that 67.4% of respondents would accept people with epilepsy as colleagues; furthermore, 82.5% reported a willingness to allow their child to play with a peer with epilepsy, and 28.0% would allow their children to marry someone with epilepsy [15].

Different studies in Arab countries have considered epilepsy as a mental disorder or a neurological disease [12–15]. Consistent with such views, the present sample cited both mental and brain disorders as key causes of epilepsy. A few (1.6%) people in our sample believed that epilepsy is a form of insanity which is relatively consistent with what has been found in Asser study (6%). Most of the studies have noted that "medical advice" is the top respondents' suggestion to be given for people with epilepsy disease [12–15]. However, 82.1% suggested that there is no need for treatment. At this stage of understanding, we believe this is due to lack of knowledge about the causes of epilepsy and poor awareness of medical services that are provided for patients with epilepsy.

The majority of respondents reporting that they "would take the person with epilepsy out of danger" if they saw this person having an epileptic attack (92.8%) which is higher than what has been reported in Majmaah (48.3%) [14]. Remarkably, there were few respondents (8.6%) believe in the use of herbal medicine for epilepsy versus (68.9%) in Asser region [12].

Table 3
Relationships among awareness, knowledge, and attitudes regarding epilepsy based on participant sociodemographic characteristics (n = 403).

	Awareness Mean ± SD	Attitudes Mean ± SD	Knowledge Mean ± SD
Gender			
• Men	4.9 ± **1.1**	7.4 ± **2.3**	5.4 ± **1.2**
• Women	4.7 ± **0.9**	7.7 ± **2.1**	05.2 ± **1.2**
p-Value[a]	***0.006*****	***0.283***	***0.055***
Age group in years			
• <30	4.6 ± **1.0**	7.7 ± **2.2**	5.2 ± **1.2**
• 30–39	4.8 ± **1.0**	7.3 ± **2.2**	5.4 ± **1.0**
• ≥40	5.1 ± **1.1**	7.4 ± **1.9**	5.2 ± **1.2**
p-Value[b]	<***0.001*****	***0.201***	***0.343***
Area of residence			
• Buraidah	4.7 ± **1.0**	7.6 ± **2.0**	5.2 ± **1.2**
• Al Badaya	4.7 ± **1.2**	7.3 ± **2.7**	5.4 ± **1.4**
• Unaizah	4.5 ± **0.9**	7.7 ± **2.2**	5.4 ± **1.1**
• Al Rass	5.0 ± **1.0**	7.3 ± **2.5**	5.4 ± **1.1**
• Al Bukairiyah	4.4 ± **0.9**	7.2 ± **2.7**	5.2 ± **0.7**
• Others	5.1 ± **0.9**	8.3 ± **1.4**	5.5 ± **1.1**
p-Value[b]	***0.073***	***0.765***	***0.703***
Marital status			
• Unmarried	4.7 ± **1.0**	7.6 ± **2.3**	5.3 ± **1.2**
• Married	4.9 ± **1.1**	7.5 ± **1.9**	5.1 ± **1.2**
p-Value[a]	***0.011*****	***0.178***	***0.133***
Education level			
• Secondary or lower	4.6 ± **1.1**	7.3 ± **2.0**	5.1 ± **1.2**
• University or higher	4.8 ± **1.0**	7.7 ± **2.2**	5.3 ± **1.2**
p-Value[a]	***0.331***	***0.067***	***0.079***
Occupation			
• Employed	4.9 ± **1.1**	7.5 ± **2.1**	5.4 ± **1.2**
• Unemployed	4.6 ± **1.0**	7.6 ± **2.2**	5.2 ± **1.2**
p-Value[a]	<***0.001*****	***0.480***	***0.020*****

SD – standard deviation.
[a] p-Value has been calculated using Mann–Whitney *U* test.
[b] p-Value has been calculated using Kruskal–Wallis 1-way analysis of variance (ANOVA).
** Significant at p ≤ 0.05.

5. Conclusion

The public's general attitudes and awareness regarding epilepsy in the present study was either good or positive; however, knowledge of this medical condition is still inadequate. Most still reported misconceptions, including the faulty claim that "epilepsy is a mental disorder." Hence, more campaigns are needed in order to increase society's epilepsy awareness, obtaining assistance from governmental agencies, health institutions, mass media, and other health-related organizations. More education on this subject will hopefully strengthen the public's understanding as to how to properly accommodate individuals living with epilepsy.

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Conflicts of interest

The authors declare that they have no conflict of interest.

Ethics approval

The ethical approval for this study was obtained from Prince Nourah Bint Abdulrahman University Research Center, Riyadh, Saudi Arabia.

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