

Public awareness and attitudes toward epilepsy in Saudi Arabia is improving

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ABSTRACT

الأهداف: تمت هذه الدراسة لتقييم درجة وعي المجتمع السعودي وانطباعاته عن مرض الصرع بمنطقة الرياض بالملكة العربية السعودية.

الطريقة: تم تحضير استبانة مكونة من 10 أسئلة مركزة لاستطلاع درجة وعي المجتمع وانطباعاته عن مرض الصرع. وقد تم إجراء مقابلات شخصية بصورة عشوائية بواسطة الباحث الرئيسي في أماكن عامة سبق تحديدها في الفترة بين مارس وأبريل 2011م.

النتائج: تم اكتمال 749 مقابلة شخصية أثناء فترة الدراسة وقد وجد أن (77.4%) من المشاركين لديهم معلومات سابقة عن الصرع و 52% تعرفوا على أنه مرض عضوي وليس نفسي. وقد ارتبط ذلك بمستواهم التعليمي حيث كان ذلك الاعتقاد أكثر لدى من كان لديهم تعليم عالي. ورغم ذلك فإن 15% ربطوا الإصابة بالصرع بالجن و 37% فضلوا العلاج الروحي والديني بدلا من العلاج الطبي. ورغم أن معظم المشاركين (61%) تقبلوا تواجد مريض الصرع بوظائف اعتيادية، إلا أن 71% منهم كان لديهم تحفظ بتزويجهم وبالذات لدى الذكور.

الخلاصة: هناك بوادر تحسن لدرجة وعي المجتمع وانطباعاته عن مرض الصرع. ولكن يظل لدى البعض أنها مرتبطة بالجن والكثير يعتقد أن العلاج الروحي فعال. وقد كشفت الدراسة عن الجهات التي يمكن التركيز عليها بالبرامج التوعوية والتثقيفية.

Objective: To examine public awareness and attitudes toward epilepsy in Riyadh, the capital city of Saudi Arabia.

Methods: A focused 10-item questionnaire was designed to survey public awareness and attitudes toward epilepsy. Personal interviews were conducted randomly by one author in preselected public places in Riyadh, Saudi Arabia during March and April 2011.

Results: Seven hundred and forty-nine interviews were completed during the study period. Most participants (77.4%) had prior knowledge of epilepsy, and 52% believed that epilepsy is an organic disease. This correlated with their educational level, as those with higher levels of education were more likely to link epilepsy to organic causes ($p=0.008$). However, 15% also linked epilepsy to evil spirit possession, and up to 37% preferred spiritual rituals and religious healing to medical treatments. Although most respondents (61%) would accept an epileptic patient in a regular job, 71% (particularly males) reported reservations in marrying someone with epilepsy ($p=0.001$).

Conclusions: The awareness and attitudes of the Saudi public toward epilepsy are showing some improvement. However, it is still thought to be linked to evil spirit possession by some, and spiritual rituals and religious healing are commonly believed to be effective treatments. Targeted areas for focused education were identified.

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Epilepsy is a common neurological disorder with potential social implications.¹ It has been linked to evils and spirits since Hippocrates, and is still largely attributed to such possession in our community.² Many of our epilepsy patients seek complementary and alternative therapies and are frequently followed by traditional healers.³ Knowledge of epilepsy leads to less stigmatization, social isolation, and depressive symptoms.⁴ Attitudes toward epilepsy are significantly influenced by knowledge of the disorder.⁵⁻⁷ Therefore, misconceptions and misinformation should be identified and corrected to help improve the quality of life of these patients. Some of the misconceptions have been reported more frequently from developing countries.⁸⁻¹¹ There is evidence that the public in Saudi Arabia is not properly informed about epilepsy and may be misinformed from unreliable sources leading to negative attitudes toward affected patients.^{11,12} Understanding the degree of public awareness and attitudes are key steps to designing educational programs and efforts to alleviate the associated social stigmata. This is a poorly studied area in our community. Our objectives were to examine public awareness and attitudes toward epilepsy, and compare our findings to the few earlier studies from Saudi Arabia.

Methods. A focused 10-item questionnaire was designed to survey public awareness and attitudes toward epilepsy (Table 1). Key questions were selected based on the available published literature and initially drafted in English and subsequently translated into Arabic. Participants were identified randomly in shopping centers and university campuses across the city of Riyadh during March 2011 and April 2011. King Fahad Medical City institutional review board approved the study design and questionnaire. The nature of the study and questionnaire were explained to the participants before voluntarily participating in the study. An assigned coauthor conducted the interviews in the preselected public places and individually assisted them to complete the questionnaires. The identity of the participants was not requested to ensure privacy and encourage accurate response. The study was explained in person, and confidentiality was assured.

Data were collected in Excel sheets and statistical analysis was performed using the Statistical Analysis System (SAS 9.3, Cary, North Carolina, USA). Descriptive analyses were performed, and the variables were examined using chi-square test. Statistical significance was defined as *p*-values of less than 0.05.

Results. During the study period, 749 participants were interviewed, 53% were males. Most participants (67%) were less than 30 years of age, and 62% had a college or university degree. Most participants (77.4%) reported having prior knowledge of epilepsy and 90% mentioned that they would treat him/her normally during social encounters. The most common source of their knowledge was based on personal experience relating to friends or relatives (28%). Many participants witnessed an epileptic seizure (50%), knew someone with epilepsy (48%), and believed that epilepsy is an organic disease (52%). This belief correlated with their educational level. Those with college or university education were more likely to link epilepsy to organic causes ($p=0.008$). However, 15% also linked epilepsy to evil spirit possession, and up to 37% preferred spiritual rituals and religious healing to medical treatment. This was more likely noted in those with lower educational levels ($p=0.013$). Although most respondents (61%) would accept an epileptic patient in a regular job, 71% reported reservations on marrying someone with epilepsy. Female participants were more likely to accept a relationship with an epileptic patient when compared with males (34% versus 23%, $p=0.001$). Finally, most participants (83%) had reservations on allowing someone with epilepsy to drive.

Discussion. Although there are considerable misconceptions about epilepsy in our community, our study suggests that public awareness and attitudes are improving. Most participants had prior knowledge about epilepsy, believed that it is an organic disease, and had reservations on allowing someone with epilepsy to drive. Their higher level of education and prior personal experience with epilepsy could explain this. We believe that current easy access to electronic media allowed many of them to witness such events. However, 15% continued to link epilepsy to evil spirit possession. This is significantly lower than the 40% rate that was reported earlier from the same Saudi region

Table 1 - Ten-item focused questionnaire on public epilepsy awareness and attitudes.

1. Do you have a prior knowledge of epilepsy?
2. What is the source of your knowledge about epilepsy?
3. Do you know a person with epilepsy?
4. Have you witnessed an epileptic seizure before?
5. What do you think is the cause of epilepsy?
6. What do you think is the appropriate treatment for epilepsy?
7. If you are an employer, would you hire someone with epilepsy?
8. Would you become engaged to someone with epilepsy?
9. How would you interact socially with someone with epilepsy?
10. Do you think that an epileptic person can/should drive a car?

by university-educated school teachers.² However, our rate is somewhat similar to that reported from neighboring gulf countries, including the United Arab Emirates (13.8%), and Kuwait (24%).^{13,14} This may explain why one third of our participants continue to prefer spiritual rituals and religious healing to medical treatment. These participants were more likely to have lower education (less than college or university degree) supporting the value of strong education in preventing such misconceptions. The correlation between the degree of knowledge and negative attitudes toward epilepsy has been well documented.¹⁵⁻¹⁷ Those with good knowledge were less likely to have negative attitudes. Another significant improvement in our sample is the rate of socially accepting someone with epilepsy. Most participants mentioned that they would treat him/her normally during social encounters and many would also accept them in a regular job. However, many reported reservations on marrying someone with epilepsy, particularly by males. This is another area that can be targeted by focused education in order to minimize the social stigma of epilepsy.

There are some limitations to our study. Although the study sample is large with equal gender distribution, it may not be representative of the Saudi public. It reflects a younger generation with higher educational levels. This may limit the ability to generalize from our findings. However, this sector of our community will likely reflect the future trend of the public in our country. Our sample also may not be representative of those living in other areas of Saudi Arabia as we only included those from the capital city of Riyadh. It will be interesting to evaluate the awareness and attitudes of those living in less urbanized regions of the country. Finally, our questionnaire was focused and short. Making it more detailed will certainly help, but may result in practical difficulties in getting busy people to agree to participate in public places.

We conclude that the awareness and attitudes of the Saudi public toward epilepsy are showing some improvement. However, epilepsy is still thought to be linked to evil spirit possession by some, and spiritual rituals and religious healing are commonly believed to be effective treatments. As well, many still have reservations on marrying someone with epilepsy, particularly by males. We were able, therefore, to identify targeted areas for focused education in order to minimize the social stigma of epilepsy. Public educational campaigns should be encouraged as this can improve the quality of life of epileptic patients and their families by helping to develop a well-informed and tolerant community.

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