Familiarity, knowledge, and attitudes towards epilepsy among attendees of a family clinic in Amman, Jordan

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ABSTRACT

الهدف: تهدف الدراسة إلى تحديد مدى معرفة الأفراد في الأردن بمرض الصرع و مدى تقبلهم لمريض الصرع بشكل عام.

الطريقة: تم مقابلة ستمائة شخص ممن يراجعون عيادات طب الاسرة وهم مراجعون لا يعانون من مرض الصرع ، ووجه لهم عدة اسئلة من خلال استبيان خاص أعد لهذه الدراسة وقد تطرق الاستبيان إلى عدة مواضيع منها المعرفة العامة بالمرض ، معرفة الاسباب ، معرفة طرق العلاج ، والوسائل التي يعتقد ان من شأنها ان تزيد من درجة الوعي العام بمرض الصرع.

النتائج: أظهرت الدراسة أن حوالي ثمانية وتسعون بالمئة من الأشخاص قد سمعوا بمرض الصرع وأن سبعة وأربعون بالمائة على معرفة بأشخاص مصابين بالمرض .وكان المصدر الرئيسي لمعلوماتهم هو أحاديث الناس العامة عن المرض.أما بالنسبة للمعرفة بالأسباب و العلاج فقد كانت المعرفة ضئيلة ، ورفض ستة و ثمانون بالمئة من الأشخاص الزواج من شخص مصاب بالصرع ، كما ورفض خمسون بالمائة منهم فكرة ان تتاح لمريض الصرع نفس فرص العمل.وأقر الغالبية بضعف معلوماتهم و جهلهم بهذا المرض و يعتقد معظمهم بان التلفاز هو خير وسيلة للتعريف بمرض الصرع.

خاتمة: بالرغم من أن هذه الدراسة لا تمثل الا شريحة معينة من المجتمع الاردني الا أنها أظهرت ضعف المعرفة بمرض الصرع وتؤكد الحاجة الى ضرورة بذل المزيد من الجهود من أجل توضيح الحقائق وإزالة الغموض عن مرض الصرع.

Objectives: To investigate the present familiarity, knowledge, and attitudes of Jordanians towards epilepsy.

Methods: This is a cross-sectional study that was conducted over a 6-month period, from April 2006 to October 2006 at the family clinic of Jordan University Hospital, Amman, Jordan. A face-to-face questionnaire interview was conducted with 600 non-epileptic adults who visited the clinic during the study period.

Results: The sample matched the overall Jordanian population for literacy rate, however, included a higher proportion of females, and consequently findings may be taken as being only moderately representative of the Jordanian population. Ninety-eight percent of the respondents had heard about epilepsy, 47.3% knew someone with epilepsy, and 39.7% had witnessed a seizure. The major source of knowledge was word of mouth; knowledge about causes and treatment were far below the results reported in western countries. In addition, negative attitudes were present with regard to marriage and employment of epileptic patients (86.8% objected to marriage and 50.8% objected to employment). Eighty-three percent of respondents admitted that their knowledge of epilepsy was not satisfactory and were willing to learn more about epilepsy. The television was believed to be the most efficient and preferred way to disseminate knowledge about epilepsy.

Conclusion: Although this study does not represent the whole Jordanian population, however, it demonstrated lack of knowledge and emphasized the extent of negative as well as positive attitudes towards epilepsy in Jordan.

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Epilepsy comes from the Greek word epilepsia, which means to be attacked or to be seized. In the Arabic language, the term used for epilepsy is called Al-Saraa. Arabic and Muslim scientists like Al-Tabari and Al-Razi described Al-Saraa (epilepsy) very clearly in their books 1000 years ago as a disease of the brain. They made a clear distinction between it and psychiatric disorders, and stated clearly that epilepsy is not related to evil spirits or supernatural powers.[1] However, in the Arabic communities, like in many other communities, epilepsy is still surrounded by many myths, misbeliefs, and

stigma. Stigma and public attitudes towards persons with epilepsy reflect general understanding and knowledge about the disorder.[2] Accordingly, it is hoped that determination of the present knowledge and attitudes towards patients with epilepsy in our community might help in the design of future efforts directed towards decreasing the stigma in Jordan. Such studies are very rare in the Arab countries,[3,4] including Jordan. This study aimed to investigate the present knowledge and attitudes of Jordanians towards epilepsy. In addition, it aimed to verify people's preferred methods through which they would like to increase their knowledge of epilepsy.

Methods. A cross-sectional study conducted over a 6-month period from April 2006 to October 2006. The study took place at the family clinic of Jordan University Hospital (JUH), Amman, Jordan. Approximately 100 patients visit this clinic every day, either alone or accompanied by others. Patients with chronic illness or epilepsy are usually not followed at this clinic. Subjects included in this study were adults aged 18-70 years who visited the family clinic during the study period. Epileptic patients were excluded from the study. Informed consent was obtained from each participant, as well as ethical approval for the study from the ethical committee of JUH. A trained person interviewed the people at the clinic and filled a preformed questionnaire; multiple answers were allowed when applicable. The questionnaire comprises 4 sections: demographics, familiarity with epilepsy, knowledge of epilepsy, and attitude towards persons with epilepsy. Most of these sections were taken from previous sections used in other published surveys so that a comparison could be made with the results from other countries. A few questions thought to be applicable to the community under study were added to the sections. A pilot study on 60 adults in the family clinic was conducted to test the questionnaire before the start of study, and only a few modifications were necessary for the final questionnaire. Although the study population was taken from a family clinic and thus does not represent the whole population, however, the sample matched the overall Jordanian population for literacy rate, but included more females. Therefore, findings may be taken to be only moderately representative of the Jordanian population.

For statistical analysis, we used the Statistical Package for Social Sciences, version 13; the chi square test was applied when indicated. In all the statistical tests, the null hypothesis was rejected at the 5% level ($p \leq 0.05$).

Results. Six hundred people were included in the study, 448 (74.7%) were women, and 152 (25.3%) were men. **Table 1** shows the demographic characteristics of the study population.

Familiarity with epilepsy. Ninety-eight percent of the respondents had heard or read about epilepsy (**Table 2**).

Knowledge of epilepsy. The aspects of knowledge tested were on causes, types, and management of epilepsy (**Table 2**). No correlation existed between higher education or older age and better knowledge of causes of epilepsy ($p>0.05$). The most frequently referenced symptom was tonic-clonic movements with loss of consciousness (**Table 2**). Regarding management of epilepsy only half of the respondents knew that medical treatment might be effective. Most of the respondents were aware of the significant advances in antiepileptic drug therapy over the past decade, as well as their teratogenic effects. However, this may have been general awareness about all drugs rather than specific awareness about antiepileptic drugs. Neither age, nor gender, nor level of education correlated with better understanding of treatment nor with fewer misbeliefs or myths regarding epilepsy ($p>0.05$).

Attitudes towards epilepsy. While most responders would allow their child to play with a child with epilepsy, only few would allow their child or any of their close relatives to marry a person with epilepsy (**Table 2**). Neither age, nor gender, nor higher level of education correlated with better attitudes towards epilepsy ($p>0.05$). In addition, many of the respondents admitted that their knowledge about epilepsy is not sufficient and were willing to learn more about epilepsy. Television was the most popular source through which respondents said they would like to receive more information on epilepsy in the future (**Table 2**).

Discussion. This study assessed familiarity, knowledge, and attitudes towards epilepsy in 600 Jordanians attending the family clinic at JUH. The study also determined possible ways through which respondents would like to receive more information about epilepsy. Most of the respondents were familiar with epilepsy. This rate of familiarity and awareness is comparable to those reported in studies from other

Table 1 - General characteristics of the study subjects.

Characteristics	N (%)
Age	
Young adults (18-39 years)	358 (59.7)
Middle aged (40-59 years)	215 (35.8)
Old aged (60-79 years)	27 (4.5)
Gender	
Female	448 (74.7)
Male	152 (25.3)
Education (years of formal education)	
Low (0-6 years)	24 (4.0)
Intermediate (7-12 years)	201 (33.5)
High (>12 years)	375 (62.5)
Employment	
Unemployed	377 (62.8)
Employed	223 (37.2)

Table 1 - Questionnaire about epilepsy (more than one answer was allowed when applicable).

Variable	Yes n (%)
Familiarity	
Have you ever heard of a disease called epilepsy	591 (98.5)
Where have you heard about epilepsy	
Word of mouth	290 (48.3)
Mass media	142 (22.7)
Books or magazines	61 (10.2)
Other sources	121 (20.2)
Have you ever had more than one seizure after the age of 5	9 (1.5)
Do you know any person who has epilepsy	284 (47.3)
Have you ever seen a person having an epileptic attack	238 (39.7)
If yes where have you seen them	
Home	44 (7.3)
Friends' house	21 (3.5)
Street	64 (10.7)
Television	79 (13.2)
Other places	171 (28.5)
Knowledge (more than one answer was allowed)	
What are the causes of epilepsy?	
Hereditary disease	344 (57.3)
Trauma	250 (41.7)
Brain cancer	56 (9.3)
Stroke	44 (7.3)
Congenital brain malformations	173 (28.8)
A mental disease	134 (22.3)
Possessed by supernatural power	85 (14.2)
Others	91 (15.2)
What are the symptoms of epilepsy?	
Tonic-colonic movements	409 (68.2)
A brief loss of consciousness	331 (55.2)
Transient change in behavior	208 (34.7)
Other	63 (10.5)
Do not know	31 (5.2)
What do you know about drug therapy for epilepsy?	
It is seldom effective in controlling seizures	334 (55.7)
It is best given as 2 or more drugs that work together	86 (14.3)
It has advanced significantly over the last 10 years	421 (70.2)
It occasionally produces malformations in babies of mothers with epilepsy	434 (72.3)
It can be stopped after seizures are controlled for a year	133 (22.2)
There is no medical treatment for epilepsy	210 (35.0)
What do you know about other modalities of treatment?	
Surgery can be beneficial	132 (22.0)
Herbal therapy can be beneficial	216 (36.0)
Wearing a metallic bracelet can help in treatment	231 (38.4)
Going to persons who deal with evil spirits can be helpful	88 (14.7)
Attitudes	
Would you allow your child to play with a child with epilepsy?	490 (81.7)
Would you allow your child or any of your close relatives to marry a person with epilepsy?	79 (13.2)
Do you think epilepsy patients should have children?	397 (66.2)
Do you think that persons with epilepsy should be employed with the same jobs as other people?	295 (49.2)
Do you think that persons with epilepsy should have a driving license?	111 (18.5)
Do you think that persons with epilepsy should get their medication free of charge?	586 (97.7)
Do you think that persons with epilepsy should have specialized centers to care for them and their needs?	582 (97.0)
Other general questions	
Do you think that your knowledge about epilepsy is insufficient?	499 (83.2)
Do you want to know more about epilepsy?	499 (83.2)
If yes, what do you think are the points you need to know?	
Causes	360 (60.0)
Symptoms	152 (25.3)
Treatment	172 (28.7)
Prophylaxis	106 (17.7)
Precipitating factors	19 (3.2)
Patients' rights	42 (7.0)
Other	26 (4.3)
What do you think is the best way to inform people about epilepsy?	
Television	515 (85.8)
Radio	52 (8.7)
Internet	121 (20.2)
Newspapers	150 (25.0)
Books	81 (13.5)
School	212 (35.3)
University	106 (17.7)
Other	33 (5.5)

developed and developing countries,[3,5-9] and it is probably related to the close interpersonal relationships in our country. However, although most of the respondents were familiar with epilepsy, their source of knowledge was not satisfactory; around 50% of their source of knowledge was word of the mouth (**Table 2**). The source of knowledge was reflected in the respondents' poor understanding of the causes and treatment of epilepsy. Knowledge of the causes of epilepsy were not satisfactory, and many still believe it is a hereditary disease (**Table 2**). Knowledge of the causes of epilepsy is below results reported in developed countries where hereditary causes and insanity were reported in 11% and 37%,[10,11] and 1% and 9%[11,12] of responses. In addition, their knowledge about treatment was insufficient; many were unaware of the medical and surgical options for treating epilepsy, and some still believe in false methods such as metallic bracelets, herbs, magic, and spirits. The patchy knowledge and prevalence of myths and misbeliefs were closer to results reported in other developing countries.[13,14] Given Jordan's high literacy rate (>90%), one would expect results of knowledge to be closer to those of developed rather than developing countries. This patchy knowledge is most likely related to the poor role that the mass media plays in Jordan. While the mass media remains the major source utilized in many countries to deliver proper knowledge about epilepsy,[15-17] the role of the mass media in Jordan seems to be unsatisfactory. Knowledge has been reported to correlate with attitudes.[18] The attitudes towards epileptic patients in our study seem to be worrisome; the percentage of the respondents who objected to the idea of a close relative marrying an epileptic patient and to similar job opportunities for epileptic patients were 86.8% and 50.8% in our study, compared with 4% and 14% reported in Canada.[12] These negative attitudes are mostly related to wrong beliefs about the causes of epilepsy. Many of the respondents believed that epilepsy is hereditary and were afraid the disease might transmit from parents to children. In addition, beliefs that epilepsy is a mental illness might have influenced the objection of equal job opportunities.

However, some positive attitudes are encouraging; almost all (98%) of the respondents agreed that epileptic patients should have specialized centers for management and should receive their medications free of charge. In addition, most of the study participants admitted that their knowledge about epilepsy is unsatisfactory and most of them expressed a desire to learn more about epilepsy. These positive attitudes might indicate that negative attitudes could be changed with time if more efforts are directed towards the transmission of proper knowledge about epilepsy in Jordan. The Jordanian league against epilepsy, along with the aid of mass media, may have the greatest influence on attitudes and the potential to decrease the stigma of epilepsy in Jordan.

In conclusion, this study demonstrated the lack of knowledge, and the extent of negative as well as positive attitudes towards epilepsy in Jordan. The study also emphasized the need for future efforts to be taken by the Jordanian league against epilepsy. Other future studies are needed to verify the patients as well as the parents knowledge of epilepsy.

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