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Knowledge and attitudes towards epilepsy in Saudi families

Hanan A. Neyaz*, Hana A. Aboauf, Maha E. Alhejaili and Mona N. Alrehaili

Faculty of Medicine and General Surgery at Taibah University, Almadinah Almunawwarah, KSA

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الملخص

أهداف البحث: مرض الصرع هو أحد أكثر أمراض الأطفال العصبية انتشارا. ولنقص الوعي بشأن مرض الصرع عند عامة الناس تأثير على حياة الأطفال المصابين بالصرع. وينبغي تحديد وتصحيح المفاهيم، والمعلومات الخاطئة عن مرض الصرع عند الأطفال. تهدف هذه الدراسة لتقييم المعرفة والسلوك تجاه مرض الصرع لدى أسر الأطفال المصابين بالصرع وأسر لأطفال سليمين في المدينة المنورة –المملكة العربية السعودية.

طرق البحث: أجريت دراسة مقطعية في مستشفى النساء والولادة والأطفال في الفترة من مارس ٢٠١٥ إلى ديسمبر ٢٠١٥. استخدمت فيها استبانة ذاتية لجمع المعلومات من الأسر المشاركة.

النتائج: من بين ١٦٨ مشاركا، استكمل ١٥٠ الاستبانة. كان هناك ٢٤ أسرة لأطفال مصابين بالصرع و ٨٦ لأسر لديها أطغال سليمين. من بين جميع الأسر المستجيبة؛ ٢٧ عائلة (٢.٤٤٪) اعتقدت وجود علاقة بين الصرع والجن. وأظهر تتطيل الانحدار اللوجستي أن هذا الاعتقاد يعتمد على مستوى تعليم الأسرة (قيمة ب = ٢٠٠٤)، ومكان الإقامة إما في المدن أو القرى (قيمة ب = ٢٠٤). ترتبط علاقة مرض الصرع بالجن عند أسر الأطفال المصابين بالصرع بالعوامل السريرية مثل نوع الصرع (قيمة ب = ٢٠٠٢)، ومدة المرض (قيمة ب = ٢٠٠٢)، ومدة العلاج (قيمة ب ح ٢٠٠٢).

الاستنتاجات: استنتجت هذه الدراسة أن مجتمعنا لا يزال لديه بعض سوء الفهم بشأن مرض الصرع حتى عند أسر الأطفال المصابين بالصرع. وهناك حاجة إلى تصحيح المعرفة والسلوك تجاه مرض الصرع. كما ينبغي عمل برامج وحملات منظمةعلى شكل تعليم شامل المجتمع.

الكلمات المفتاحية: مرض الصرع؛ الأطفال المصابون بالصرع؛ نوع الصرع؛ تعليم المجتمع

E-mail: h-neyaz@hotmail.com (H.A. Neyaz) Peer review under responsibility of Taibah University.

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Abstract

Objectives: Epilepsy is one of the most common paediatric neurological disorders. Lack of awareness regarding epilepsy among the general population influences the lives of epileptic children. Misconceptions and misinformation about epilepsy in children should be identified and corrected. The aim of this study was to assess the knowledge and attitudes towards epilepsy in families of epileptic children and families of normal children in Almadinah Almunawwarah, KSA.

Methods: A cross-sectional study was conducted at Maternity and Children's Hospital from March 2015 to December 2015. A self-administered questionnaire was designed to collect data from the participant families.

Results: Of 168 participants, 150 completed the questionnaire. These included 64 families of epileptic children and 86 families of normal children. Of all the responding families, 67 families (44.7%) thought that epilepsy was related to Jinn. Logistic regression analysis showed that this belief was dependent on the family education level (p = 0.004) and to the area of residence, either urban or rural (p = 0.04). In families of epileptic children, the link of epilepsy to Jinn was related to clinical factors, such as the type of epilepsy (p = 0.023), disease duration (p = 0.039), and duration of treatment (p = 0.028).

Conclusions: Our community still has misconceptions regarding epilepsy, even among families of epileptic children. Knowledge and attitudes toward epilepsy must be corrected. Planned programs and campaigns should be conducted in the form of mass society education.

Keywords: Epilepsy; Epileptic children; Jinn; Society education; Type of epilepsy

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^{*} Corresponding address: Faculty of Medicine and General Surgery at Taibah University, 6327 Al-Iskan Unit No: 1, Almadinah Almunawwarah 42317, KSA.

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Introduction

Epilepsy, defined as recurrent unprovoked seizures, is one of the most common paediatric neurological disorders and has a prevalence of 4–8 cases per 1000 children.^{1,2} Epileptic seizures are generated from excessive and abnormal cortical nerve cell activity in the brain.³ Most cases of epilepsy are idiopathic; however, some cases may be a result of brain injury, stroke, brain tumour, or drugs/alcohol abuse. In addition, certain genetic mutations have been identified as the cause of some cases of epilepsy.⁴ Since Hippocrates, epilepsy has been linked to evils and spirits, and in our community, epilepsy is still largely attributed to such possession.⁵ As such, many epileptic patients seek complementary and alternative therapies from traditional healers.⁶

The lack of awareness regarding epilepsy among the general population, and even among health care professionals, has been demonstrated in several studies.^{7,8} For instance, cultural background and education level were found to influence one's attitude towards epilepsy.^{9,10} Knowledge about epilepsy is associated with less perceived stigmatisation and social isolation, as well as fewer depressive symptoms and misconceptions.^{11,12} Moreover, parents' degree of knowledge regarding epilepsy affects their attitudes towards their epileptic children.^{13,14} of Common examples misconceptions include overprotection of epileptic children by preventing them from going to school and participating in sports or social activities.^{15,16} This can result in adaptation problems, depression and negative effects on the whole family.¹⁷⁻¹⁹ Adequate education is the corner stone in managing these patients and their families.^{2,20}

To optimally care for epileptic children, all misconceptions and misinformation should be identified and corrected. The aim of this study was to assess the knowledge and attitudes towards epilepsy among families of epileptic children as well as in families of healthy children in Almadinah Almunawwarah region, KSA, and to compare these findings to the results that have been published from other localities in KSA and in other countries.

Materials and Methods

A prospective observational study was carried out at Maternity and Children Hospital (MCH), Almadinah Almunawwarah, KSA from March 2015 to December 2015.

The instrument used in this study was a self-administered questionnaire. Development of this instrument included an initial preparatory phase, a pilot study phase and a final revision phase. In the preparatory phase, we conducted a thorough literature search and revised published studies concerning the assessment of, and knowledge and attitude towards, epilepsy in the general population and in families with epileptic children.^{21–24} We then designed a simple

questionnaire to evaluate the families' knowledge about the basic facts regarding epilepsy and their attitude towards epileptic children. The questionnaire was designed to apply to both families of epileptic and normal children. All included questions were designed to match the common beliefs and customs that are common in our locality. The questionnaire was prepared in a simple and clear Arabic language. Questions to assess the socioepidemiological characteristics of the families were also added. Additionally, questions specific to families of epileptic children were added to collect data regarding the type and course of the disease in their children. The questionnaire was subjected to internal revision to check its validity. This revision was conducted by a neurology expert Dr. Muhammad Imam who reviewed the significance of each included question and the overall inclusion of the applicable aspects necessary to assess knowledge and attitudes toward epilepsy. Next, we conducted a pilot study on 15 families of epileptic child and 15 families of normal children to check the reliability of the questionnaire. Any vague or confusion in understanding the questions were modified appropriately.

The final revision was then used in the primary study.

The questionnaire includes three sections. The first section addresses the socioepidemiological characteristics of the families. The second section contains seventeen questions about the knowledge and attitudes of the families towards epilepsy. The third section includes seven questions specific to families of epileptic patients. Most of the questions employ a yes/no format; however, some questions provided multiple choices from which to choose a response.

Both mothers and/or fathers completed the questionnaire, depending on who accompanied the child to the outpatient clinic. We did not administer the questionnaire to other accompanying extended family members, such as uncles and grandparents. We found no differences in the data between mothers and fathers.

Data management

Data were coded and analysed using the Statistical Package for the Social Sciences (SPSS) version 19 (IBM, 2010). The data are presented as the means \pm standard deviations (SD) for quantitative data and frequency and proportions for qualitative data. Student's t- test was used to compare quantitative data between the two groups, while the Chi-square test was used for between-group comparisons of qualitative data. Logistic regression was used to find the relationship between different socioepidemiological parameters and common beliefs and attitudes towards epilepsy. The threshold of statistical significance was set at *p* value less than 0.05.

Ethical issues

We obtained informed consent from each participant after explaining the study objectives. Ethical permission to carry out the study was granted by the Research Ethical Committee (REC) of Taibah University and Maternity and Children's Hospital in Almadinah Almunawwarah, KSA. Confidentiality of the data was ensured for all participants.

Results

Residency

A total of 168 self-administered questionnaires were distributed to families during the study period. Eighteen questionnaires were excluded due to incomplete data, so 150 questionnaires were included for data analysis; 64 were obtained from families of epileptic children, and 86 were from families of healthy children. The sociodemographic characteristics of all of the enrolled families are shown in Table (A1), Figure (A2). There was no significant difference between families of epileptic and non-epileptic children regarding the education level, employment, or residency; however, families of epileptic children tended to be older than those of healthy children.

Knowledge about the aetiology of epilepsy

For families across both groups, 64 families (42.7%) responded that they knew the cause of epilepsy; only 2 families (1.3%) thought that epilepsy is contagious, 86 families (57.3%) thought it is a heritable disease, 65 families (43.3%) thought it is a mental illness and 67 families (44.7%) thought it is related to Jinn.

Logistic regression analysis across groups showed that the idea that epilepsy is related to or caused by Jinn was significantly dependent on the education level of the family (p = 0.004) and the area of residence, urban or rural, (p = 0.04). The age of the caregivers, family income and employment were insignificant factors.

Inside Almadinah Almunawwarah

Outside Almadinah Almunawwarah

Knowledge about the outcome and treatment of epilepsy

With the two groups combined, 94 families (62.7%) believed that epilepsy may lead to death and 129 families (86%) believed that it is curable. One-hundred-thirty families (86.7%) thought that epilepsy is best treated by medications, while 23 families (15.3%) believed that traditional treatment (such as cautery) can help. Only 13 families (8.7%) thought that there is a surgical treatment for epilepsy. A statistically significant difference existed between families of epileptic and normal children regarding their belief about the outcome of epilepsy; more families of epileptic children (93.8%) thought that epilepsy can be cured (p = 0.018), see Table (B1), Figure (B2).

Knowledge about how to perform first aid

Less than half the respondent families (46.7%) knew how to perform first aid for a convulsing patient; these included 40 families (62.5%) of epileptic children and 30 families (34.9%) of normal children, a statistically significant difference between the two groups (p = 0.001). Logistic regression analysis showed that knowledge about how to perform first aid to a child during an epileptic episode was not related to the age of the caregiver, education level, residence, or occupation. Families who knew how to perform first aid had learnt from their doctors (44 families), the internet (17 families), media sources (15 families) or other sources (15 families).

54 (84.4%)

10 (15.6%)

.890

Table A1: The sociodemographic characteristics of the studied families.				
Variable		Family of non-epileptic child	Family of epileptic child	P values
Age	20-30	41 (47.7%)	18 (28.1%)	.005
-	31-40	33 (38.4%)	28 (43.8%)	
	41-50	11 (12.8%)	15 (23.4%)	
	51-60	1 (1.2%)	3 (4.7%)	
Education	Illiterate	3 (3.5%)	7 (10.9%)	.180
	Elementary	5 (5.8%)	6 (9.4%)	
	Secondary	15 (17.4%)	5 (7.8%)	
	Higher education and above	63 (73.3%)	46 (71.9%)	
Work	Worker	36 (41.6%)	32 (50%)	.325
	Non-worker	50 (58.1%)	32 (50%)	

72 (83.7%)

14 (16.3%)

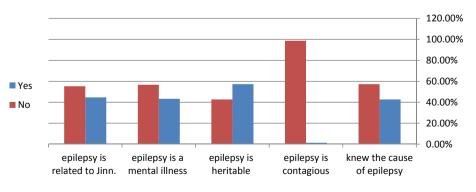


Figure A2: Knowledge about the etiology of epilepsy among the studied families.

Variable		Family of non- epileptic child	Family of epileptic child	P values
Do you think non-medical treatment (beating and cautery)	Yes	12 (14%)	10 (15.6%)	.624
should be considered for epilepsy?	No	74 (86%)	54 (84.4%)	
Do you think an epileptic child needs to be treated differently?	Yes	68 (79.1%)	47 (73.4%)	.423
	No	18 (20.9%)	17 (26.6%)	
Do you think an epileptic child has the capability for school achievement?	Yes	78 (90.7%)	54 (84.4%)	.241
	No	8 (9.3%)	10 (15.6%)	
Do you think an epileptic child can participate in any type of sport?	Yes	62 (72.1%)	53 (82.8%)	.126
	No	24 (27.9%)	11 (17.2%)	
Do you think epileptic drugs affect patient life?	Yes	40 (46.5%)	30 (46.9%)	.965
	No	46 (53.5%)	34 (53.1%)	
Do you think epileptic drugs affect patient school achievement?	Yes	25 (29.1%)	20 (31.3%)	.775
	No	61 (70.9%)	44 (68.8%)	
Do you think epileptic drugs affect an epileptic child's activity?	Yes	44 (51.2%)	44 (68.8%)	.031
	No	42 (48.8%)	20 (31.3%)	
Do you think this disease will affect an epileptic child's life?	Yes	68 (79.1%)	46 (71.9%)	.311
	No	18 (20.9%)	18 (28.1%)	

Table B1: Knowledge and attitudes towards epilepsy among families of epileptic children and families of normal children.

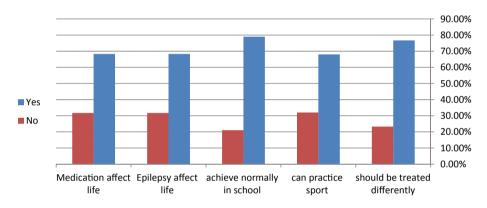


Figure B2: Attitudes towards epilepsy among the respondent families.

Epileptics should be treated differently

Of all the included families, 115 (76.7%) believed that epileptic children should be treated differently, with no statistically significant difference between the families of epileptic and normal children. This belief was not related to the age of the caregiver, education level, residence, or occupation (Table C1).

Epileptics can play sports

One-hundred-fifteen of 150 families (76.7%) thought that epileptic children could participate in type of sport, with no statistically significant difference between families of epileptic and healthy children.

Epileptics have normal school achievements

Of the responding families, 132 families (88.0%) believed that epileptic children can have good achievement at school, while 18 families (12.0%) thought that they cannot. No difference existed between the families of epileptic and healthy children in this respect.

Epilepsy affects life

Of all of the families, 36 (24.0%) thought that epilepsy affects a patient's life, while 114 (76.0%) responded that it does not. Of those families, 46 (77.9%) were epileptic child families, while 68 (79.1%) of them belonged to healthy children and such difference was statistically insignificant.

Data regarding the epileptic children

Table D1 contains some clinical data of epileptic children participate in the study.

Logistic regression analysis of some clinical data and their relation to different beliefs and attitudes towards epilepsy showed that the belief that epilepsy is related to Jinn was linked to the type of epilepsy (p = 0.023), disease duration (p = 0.039), and treatment duration (p = 0.028). The idea that epilepsy may affect a child's life was only related to the age of the child (p = 0.049). Also, child age (p = 0.01) and illness duration (p = 0.042) were determinant factors of the family belief that medication will affect the life of their child.

Table C1: Attitudes towards	epilepsy in families o	f epileptic children and	families of normal children.
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Variable		Family of non- epileptic child	Family of epileptic child	P values
Do you know what the cause of epilepsy is?	Yes	31 (36%)	33 (51.6%)	.058
	No	55 (64%)	31 (48.4%)	
Do you think epilepsy is a contagious disease?	Yes	2 (2.3%)	0 (0%)	.222
	No	84 (97.7%)	64 (100%)	
Do you think epilepsy is a heritable disease?	Yes	56 (65.1%)	30 (46.9%)	.025
	No	30 (34.9%)	34 (53.1%)	
Do you think epilepsy is a mental disease?	Yes	34 (39.5%)	31 (48.4%)	.280
	No	52 (60.5%)	33 (51.6%)	
Do you think epilepsy can be due to Jens?	Yes	40 (46.5%)	27 (42.2%)	.601
	No	46 (53.5%)	37 (57.8%)	
Do you think epilepsy can cause death?	Yes	56 (65.1%)	38 (59.4%)	.475
	No	30 (34.9%)	26 (40.6%)	
Do you think epilepsy is a curable disease?	Yes	69 (80.2%)	60 (93.8%)	.018
	No	17 (19.8%)	4 (6.3)	
What is the best treatment?	Drugs	72 (83.7%)	58 (90.6%)	.221
	Surgical	5 (5.8%)	8 (12.5%)	.152
	Traditional medicine	18 (20.9%)	5 (7.8%)	.027
	Others	8 (9.3%)	8 (12.5%)	.534
Do you know how to do first aid for a	Yes	30 (34.9%)	40 (62.5%)	.001
child during an attack?	No	56 (65.1%)	24 (37.5%)	

Variable			
Age of epileptic child	<1 year-5 years 20 (31		
	6 years-10 years	29 (45.3%)	
	11 years-15 years	14 (21.9%)	
	16 years-20 years	1 (1.6%)	
Duration of the disease	<1 year	11 (17.2%)	
	1 year-5 years	33 (51.6%)	
	6 years-10 years	16 (25%)	
	>10 years	4 (6.3%)	
Duration of the treatment	<1 year	16 (25%)	
	1 year-5 years	31 (48.4%)	
	6 years-10 years	14 (21.9%)	
	>10 years	3 (4.7%)	
Type of epilepsy	Generalized	31 (48.4%)	
	Partial	33 (51.6%)	
Type of medication	Keppra	21 (32.8%)	
	Depakine	30 (46.9%)	
	Topamex	12 (18.8%)	
	Others	30 (46.9%)	
Did you ever treat your	Yes	9 (41.1%)	
child by beating or cautery?	No	55 (85.9%)	
Is there any other family	Yes	14 (21.9%)	
member diagnosed with epilepsy	No	50 (78.1%)	

Discussion

The general population's knowledge and attitudes towards epilepsy play a major role in determining the extent to which epileptic patients can be integrated into their societies. In developing communities, there are many false beliefs and misconceptions regarding epilepsy in the general population as well as among families of epileptic patients.²⁵ To our knowledge, this is the first study to evaluate the level of knowledge and attitudes towards epilepsy in families of epileptic children and families of healthy children in Almadinah Almunawwarah region, KSA.

In our study, nearly half (44.7%) of the respondent families believed that epilepsy is related to Jinn. Similar results have been reported in studies conducted in different regions of KSA. In Jeddah, for instance, Obeid and his colleagues reported that 40.3% of school teachers and 50.4% of students in their sample believed that epilepsy may be caused by Jinn.⁵ Also, Zaini and her colleagues, in a study conducted at the paediatric neurology out-patient clinic of King Abdul-Aziz University hospital, Jeddah, reported that 44% of epileptic parents believed that epilepsy is associated with evil.²⁶

People's beliefs linking epilepsy to supernatural powers and Jinn have been reported in several studies conducted in different countries. In Sudan, Inaam et al. stated that 32.2% of their sample thought that the main cause of epilepsy is the supernatural linked with an evil spirit and demonic attack.²⁷ In another study conducted in Pakistan and Turkey, only 3% of patients in Pakistan but 71% of patients in Turkey believed that their illness was due to supernatural causes.²⁸ Variations observed during these studies may have been related to different cultural or educational levels of the studied population.

In the present study, logistic regression analysis showed that the idea of relating epilepsy to Jinn in all of the studied families was significantly dependent on the education level (p = 0.004) and area of residence, urban or rural, (p = 0.04). Our findings are consistent with those from many other studies in which high educational levels were found to correlate positively with knowledge of epilepsy. In Malaysia, Neni, et al. stated that respondents with higher education significantly possessed higher total AKA (awareness, knowledge and attitudes) levels compared to those with lower education levels (p < 0.001).²¹ Also, we found that, in families of epileptic children, the belief that epilepsy is related to Jinn was more prevalent in families of children having a

longer disease duration, a complex presentation of epilepsy, or who required multiple antiepileptic medications. It may be reasonable to consider that the vagueness of epilepsy presentations, unclear aetiology and poor response to medication may, partly, contribute to the families' search for a supernatural power to explain what science could not.

In the current study, a high proportion of respondents (86.7%) believed that epilepsy should be treated medically and (86%) stated that it is curable. However, 15.3% still believed in the value of traditional medicine in treating epilepsy. Reports from previous studies examining people's beliefs about using traditional medicines, such as herbal therapy and cautery, to manage epilepsy have been inconsistent. Alageel and Sabbagh reported that 14.6% of the participants in a study conducted in Riyadh considered herbal therapy as a part of epilepsy treatment.²⁹ In a Jeddah study, 24% of school teachers and 27.9% of university students considered herbs as part of epilepsy treatment.⁵ A higher proportion of participant beliefs in the value of epilepsy was reported in the studies conducted in Arar $(45.2\%)^{30}$ and Sudan (42.5%).²⁷ Again, this could be related to education level, as these studies were conducted in rural areas where people mostly had lower education levels.

Most of the respondents in our study did not appreciate the role of surgical treatment in epilepsy because only 12.5% of families of epileptic children and 5.8% of families of normal children said that epilepsy can be treated surgically. Similar results were obtained in a study conducted in Riyadh (7.4%),²⁹ while in a Jeddah study, a higher percentage (41%) of respondents considered surgery as a treatment option for epilepsy.²⁶

In the present study, less than half of the respondent families knew how to perform first aid for a convulsive child, and most of these were families of epileptic children. Most families received their information about first aid management from their doctors. This emphasises the important role of doctors in family and patient education. No previous studies in KSA have evaluated the role of the treating physician in educating families about how to perform first aid management during convulsions.

Generally, most of the included families in our study had a positive attitude towards epilepsy; 88% of responding families believed that epileptic children could have normal school achievement and 76.7% believed that epileptic children can participate in sports. Alageel and his colleagues reported similar results in their study conducted in Riyadh regarding the ability of epileptic children to be successful in a normal classroom.²⁹ In contrast, in an Italian study, 48% of the respondents did not agree that patients should participate in sports.³¹ On the other hand, a higher percentage of the respondent families in our study believed that epileptic children should be treated differently than what was reported by Zaini et al. in a Jeddah study.²⁶ This difference could be attributed to the inclusion in our study of families of non-epileptic children, which were not included in the other study.

Study limitation

There has been no previously published statistical data regarding the prevalence of epilepsy in Almadinah

Almunawwarah region, KSA. Although the number of families that participated in our study was significant and the MCH is considered to be a referral centre for a large population area, a larger multicentre study may be needed to verify the results obtained in our study.

Conclusions

Our community still has some misconceptions regarding epilepsy, even in families of epileptic children, and logistic regression analysis suggests that most of the misconceptions have been due to relating epilepsy to Jinn. Knowledge and attitudes towards epilepsy must be corrected. Planned programs and campaigns need to be conducted for mass society education. Doctors and health educators have a major responsibility to correct these misconceptions and educate the patients and their families regarding the disease and its proper management.

Conflict of interest

The authors have no conflict of interest to declare.

Authors' contribution

HAN provided research materials, collected and analyzed data, conducted research results and participated in writing the discussion. HAN provided research materials, collected and analyzed data, conducted research results, participated in writing of introduction and discussion. MEA collected and analyzed data, conducted research results and participated in writing the introduction, discussion and conclusions. MNA collected and analyzed data, conducted research results and participated in writing research methodology, discussion, conclusions, acknowledgement and study limitations.

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