Awareness and attitude about epilepsy among Iraqi epileptic's families.

Sensibilisation et attitude à l'égard de l'épilepsie parmi les familles épileptiques irakiennes.

Ghaieb Aljandeel[1], Mohammad Kamil[2], Hula Shareef[3]
1- Iraqi Council for Higher Medical Specializations, Baghdad, (Iraq)
2- Fallujah University, College of Medicine, AL-Anbar, (Iraq)
3- Child Welfare Hospital, Medical City, Baghdad, (Iraq)
Email: aljandeel@hotmail.com
Conflict of interest: aucun

Abstract:

Purpose:

This study is designed to evaluate knowledge and attitudes towards epilepsy among families with people with epilepsy in Baghdad city and its vicinity.

Methods:

This descriptive study involved 400 families with one epileptic member or more, who consult private or public outpatient clinics in Baghdad city; a questionnaire with close-ended questions was distributed to caregivers. It comprised three parts, one for demographic data, the second for measuring the knowledge about epilepsy and a third to evaluate the attitudes towards epilepsy. The data was analyzed by using the Statistical package for social Sciences (SPSS).

Results:

The 400 participants of caregivers were fathers (40.5%) or mothers (32%); the majority (77.8%) are living in urban districts. The overall level of knowledge about epilepsy was moderate (67.8%) with a score of (43-61), or low (19.5%) with a score of (26-42) whereas the overall assessment level of attitudes towards epilepsy was mainly positive in 67.85 of families or neutral in 29%; it was negative in 3.3% of participants only. With regards to demographic data, a high relation was noted for the educational level with knowledge (r=0.71), and to a lesser extent, with attitudes (r=0.58); and for monthly income with knowledge (r=0.68), or with attitudes (r=0.69). Marital status was moderately related with knowledge (r=0.56), and weakly with attitudes (0.47); age was weakly related with both knowledge and attitudes.

Conclusion:

Higher educational level and socioeconomic status were associated with greater knowledge and more favorable attitudes towards epilepsy whereas no significant relation was found with respect to age or occupation.

Keywords: Attitude - Awareness - Education - Epilepsy - Knowledge.

Résumé :

Objectif :

Cette étude vise à évaluer les connaissances et les attitudes à l'égard de l'épilepsie des familles qui ont des membres épileptiques dans la ville de Bagdad et ses environs.

Méthodes :

Cette étude descriptive a impliqué 400 familles avec un membre épileptique ou plus, qui consultent des patients ambulatoires privés ou gouvernementaux dans la ville de Bagdad ; un questionnaire avec des questions fermées a été distribué aux aidants. Il était composé de trois parties, une pour les données démographiques, la seconde pour mesurer les connaissances sur l'épilepsie et une troisième pour évaluer les attitudes à l'égard de l'épilepsie. Les données ont été analysées à l'aide de la version du progiciel statistique pour les sciences sociales (SPSS).

Résultats :

Les 400 participants des soignants étaient des pères (40,5%) ou des mères (32%) ; la majorité (77,8%) vit dans des quartiers urbains. Le niveau global de connaissance sur l'épilepsie était modéré (67,8%) avec un score de (43-61), ou faible (19,5%) avec un score de (26-42) alors que le niveau global d'évaluation des attitudes à l'égard de l'épilepsie était principalement positif dans 67,85 des familles ou neutre dans 29% ; il était négatif chez 3,3% des participants seulement. En ce qui concerne les données démographiques, une relation élevée a été notée pour le niveau d'éducation avec les connaissances (r = 0,71), avec les attitudes dans une moindre mesure (r = 0,58), et pour le revenu mensuel avec connaissances (r = 0,68), avec les attitudes (r = 0,69). L'état matrimonial était modérément lié aux connaissances (r = 0,56) mais faiblement aux attitudes (0,47) ; l'âge était faiblement lié à la fois aux connaissances et aux attitudes.

Conclusion :

Un niveau d'éducation et un statut socio-économique plus élevés étaient associés à une meilleure connaissance et à des attitudes plus favorables à l'égard de l'épilepsie, alors qu'aucune relation significative n'a été trouvée en ce qui concerne l'âge ou la profession.

Mots-clés : Attitude - Connaissance - Education - Epilepsie - Sensibilisation.

Introduction:

Epilepsy is one of the oldest known brain disorders [1]. It is characterized by a continuous predisposition to generate epileptic seizures, usually leading to neurologic, cognitive, psychological and social consequences. To be diagnosed epileptic, one has to have suffered at least one epileptic seizure [2].

Although epilepsy is one of the most prevalent neurological diseases, it is still surrounded by stigmas and prejudice among the population. It has been suggested that much of the discrimination against people with epilepsy (PWE) is motivated by the mistaken beliefs of impotence, fragility and mental impairments of patients [3].

The public awareness and understanding of a medical illness including epilepsy is crucial in the prophylaxis, early diagno-

sis, treatment and compliance with therapy. The lack of knowledge about epilepsy has been considered to be an important determining factor in the generation of negative attitudes towards PWE [4]; studies on public awareness, attitudes and knowledge about epilepsy are useful in decreasing discrimination and stigmatization. An accurate knowledge of the public attitudes towards epilepsy is important as misconception and social misunderstanding may affect the QOL of the patients more than the disease itself. People with epilepsy are at risk of developing a variety of psychological problems including depression, anxiety, and psychosis [5].

Sociocultural attitudes continue to have a negative impact on management of epilepsy [6]. The disorder is enmeshed in superstition, discrimination and stigma in many countries in Asia and Africa [7]. Religious and sociocultural beliefs influence the nature of treatment and care received by PWE. Many countries in Africa and Asia and other developing countries believe that epilepsy results from witchcraft or possession by evil spirits and therefore treatment should be through traditional experts, fetish priests and religious leaders [6].

Epileptic people suffer untold social deprivations and discrimination in education, employment, marital life and different social aspects [8].

The committee of 'Epilepsy Awareness' in the ILAE-EMR intended to study parents' level of knowledge and attitudes towards epilepsy. Researchers from the Iraqi chapter against epilepsy (IqLAE) carried out a study in the Iraqi Capital Baghdad to measure the awareness and attitudes of Iraqi families with persons with epilepsy towards the condition. A questionnaire was constructed including a number of questions arranged to explore the knowledge about epilepsy of families having one or more epileptic members in the family, and also the attitude of those families about the different aspects of epilepsy like first aids when a grand mal seizure occurs at home, or the social attitude towards epileptic patients regarding occupations, marriage, and other aspects of life.

Objectives of the study:

To assess family knowledge and family attitudes about epilepsy and to determine the relationship between knowledge and attitudes towards epilepsy.

Methods:

A descriptive-analytical study was conducted to assess the knowledge about epilepsy, and the attitudes towards epileptic patients of some Iraqi families who have one or more members suffering from epilepsy. This design was carried out in order to achieve the objectives of the present study.

The sample of the study consisted of 400 epileptic families in Baghdad city and surrounding area who were attending outpatient clinics (private and public) in Baghdad. The study was conducted over a period of 7 months, from the 1st of July 2020 to the 30th of January 2021.

A questionnaire was constructed by the researchers for the purpose of the study. It consisted of three parts:

Part I: socio-demographic Data sheet.

Included information regarding gender, age, residence, social status, occupation, financial state and level of education.

Part II: family knowledge.

Consisted of 26 items that measure the level of family knowledge about epilepsy.

Part III: family attitude.

Consisted of 8 items that measure the attitudes of the family towards PWE.

The total items were 34.

An interview technique was used for data collection; the questionnaire was administered to parents or caregivers who received the instructions from the researchers to fulfill the questionnaire. The data was analyzed by using the Statistical Package for Social Sciences (SPSS) version (which version?)

Results:

Results of the study

Table 1: Distribution of the Study Sample by their demographic data (N =400).

Demographical data	Ranking and Interval	Frequency	Percentage %
Age/Year	16-26	54	13.5
	27-37	113	28.3
	38-48	**135**	**33.8**
	49-59	65	16.3
	60-70	33	8.3
	Total	400	100.0
Care provider	**Father**	**162**	**40.5**
	Mother	128	32.0
	Other	110	27.5
	Total	400	100.0
Residential area	**Urban**	**311**	**77.8**
	Rural	89	22.2
	Total	400	100.
Marital status	**Married**	318	79.5
	divorce	14	3.5
	Widow	30	7.5
	Separated	38	9.5
	Total	400	100.0
Educational level	Illiterate	21	5.3
	Primary school	83	20.8
	Secondary school	149	37.3
	College or Institutes	147	36.8
	Total	400	100.0
Income monthly	Enough	164	41.0
	Almost enough	174	43.5
	Not enough	62	15.5
	Total	400	100.0
Occupation	**Officer**	**144**	**36.0**
	Kasib	77	19.3
	Retired	37	9.3
	Free jobs	43	10.8
	Other	99	24.8
	Total	400	100.0

Number of children	**1-3**	**266**	**66.5**
	4-7	133	33.3
	8-10	1	.3
	Total	**400**	**100.0**

This table of demographic data for the caregivers shows that they are mainly fathers (40.5%); the majority (77.8%) are residents of urban districts whereas 79.5% of them are married. The table also shows that caregivers are mainly secondary school graduates followed by institute or college graduates; monthly income was enough or almost enough in 84.5% of sample families.

Table 2: Distribution of study sample's knowledge concerning epilepsy (N=400).

No	Items	Yes	Not sure	No	M	S.D
1-	Do you read or hear about epilepsy before?	40.5%	7.3%	52.3%	2.12	.957
2-	Is epilepsy a psychiatric disease?	50.8%	30.8%	18.5%	1.68	.768
3-	Is epilepsy an infectious disease?	4.3%	22.3%	73.5%	2.69	.547
4-	Is epilepsy a hereditary disease?	46.3%	27.5%	26.3%	1.80	.829
5-	Is epilepsy related to Jinn?	13.5%	23.8%	62.8%	2.49	.722
6-	Is marriage of related people, a main reason?	39.0%	30.5%	30.5%	1.92	.830
7-	Is there non-medical therapy for epilepsy like herbs?	22.3%	30.3%	47.5%	2.25	.797
8-	Are anti-seizure drugs special?	5.5%	23.5%	71.0%	2.66	.580
9-	May It be treated by surgery?	10.3%	51.8%	38.0%	2.28	.638
10-	May it be cured completely?	35.8%	42.8%	21.5%	1.86	.744
11-	Do seizures occur in children only?	19.5%	16.0%	64.5%	2.45	.799
12-	Does epilepsy affect intelligence?	37.8%	19.0%	43.3%	2.05	.899
13-	May more than one patient be in one family?	15.5%	17.8%	66.8%	2.51	.749
14-	Can epileptics have any job?	49.3%	14.0%	36.8%	1.88	.920
15-	Can epileptics marry?	12.3%	15.3%	72.5%	2.60	.697
16-	Can epileptics have offspring?	12.0%	19.8%	68.3%	2.56	.698
17-	Epilepsy of mother can affect the fetus.	17.8%	37.5%	44.8%	2.27	.744
18-	Epileptic mother can breastfeed.	25.0%	29.3%	45.8%	2.21	.816
19-	Do you put a piece of cloth in patient's mouth?	29.0%	9.0%	62.0%	2.33	.896
20-	Do you make a massage for limbs?	28.3%	10.0%	61.8%	2.33	.889
21-	Do you press on the nose of the patient?	39.8%	17.3%	43.0%	2.03	.910
22-	Do you turn the patient aside?	30.5%	13.3%	56.3%	2.26	.896
23-	Do you open the tie and belt of the patient?	21.5%	6.3%	72.3%	2.51	.826
24-	Do you wash his face with water?	13.0%	4.0%	83.0%	2.70	.686
25-	Do you try to resist his limb movements?	72.3%	5.5%	22.3%	1.50	.835
26-	Do you transfer him to hospital?	26.8%	4.8%	68.5%	2.42	.883

S.D = standard de viation , M = mean

This table shows distribution of sample knowledge concerning epilepsy.

Table 3: Overall assessment level of knowledge toward epilepsy (N= 400).

Overall knowledge	Frequency	Percent
Poor	78	19.5
Moderate	**271**	**67.8**
Good	51	12.8
Total	400	100.0

Low = (26-42), Moderate = (43-61), High = (62-78).

The analysis of this table reveals that overall knowledge of sample families were moderate level (score of 43-61) with a percentage of 67/8% while 19.5% of them were of poor level (score of 26-42).

Table 4: Distribution of study sample's attitudes towards epilepsy. (N=400)

No	Items	Agree	Neutral	Disagree	M	S. D
1-	You wish you don't have the epileptic son	27.8%	4.3%	68.0%	2.40	.893
2-	You feel epilepsy of your kids a stigma	10.3%	3.3%	86.5%	2.76	.622
3-	You treat your epileptic kids differently	17.0%	1.8%	81.3%	2.64	.756
4-	You feel embarrassed on asking you about your epileptic son	25.5%	1.3%	73.3%	2.48	.873
5-	You don't punish him on making a mistake	23.5%	2.5%	74.0%	2.51	.850
6-	The epileptic patient should stay home always	26.8%	6.3%	67.0%	2.40	.882
7-	Should be enrolled in special schools	36.5%	16.5%	47.0%	2.10	.909

8-	You believe in religious people to cure your patient	20.3%	10.3%	69.5%	2.49	.810
S. D= standard deviation, M= mean.						

This table shows the distribution of sample's attitudes towards epilepsy; the table shows the means and standard deviations .

Table 5: Overall assessment level of attitudes status toward epilepsy

Overall attitudes	Frequency	Percent
Negative	13	3.3
Neutral	116	29.0
Positive	**271**	**67.8**
Total	400	100.0
Negative = (1-1.66), Neutral = (1.67-2.33), Positive= (2.34-3).		

The table illustrates the overall assessment level of attitudes towards epilepsy; it reveals that the majority of sample families have positive attitudes (67.8%) while 3.3 % shows negative attitudes.

Table 6: Relationship between knowledge and attitudes towards epilepsy.

Overall knowledge * Attitudes	P. Value		
	X2	df	Sig
	22.032	4	**0.001**
X2 = Chi-square value, P value ≤ 0.05			

This table shows the relationship between knowledge and attitudes towards epilepsy; it reveals a highly significant relationship between the knowledge and the attitudes among sample families towards epilepsy at p<0.005.

Table 7: shows the correlation between sample demographical data and knowledge.

Age / **sample knowledge**	**Poor**	**Moderate**	**God**	**Total**
16-26	21	28	5	54
27-37	28	75	10	113
38-48	29	81	25	135
49-59	21	38	6	65
60-70	7	21	5	33
Correlation (r=)0.31	106	243	51	400
Marital status / **sample knowledge**	**Poor**	**Moderate**	**God**	**Total**
Married	81	193	44	318
Divorce	3	10	1	14
Widow	11	18	1	30
Separated	11	22	5	38
Correlation (r=)0.56	106	243	51	400
Income monthly / **sample knowledge**	**Poor**	**Moderate**	**God**	**Total**
Satisfied	40	102	22	164
Satisfied to some extent	43	104	27	174
Unsatisfied	23	37	2	62
Correlation (r=)0.68	106	243	51	400
Education level / **sample knowledge**	**Poor**	**Moderate**	**God**	**Total**
Not read, Not write	5	16	0	21
Primary	31	49	3	83
Secondary	41	89	19	149
Bachelor and above	29	89	29	147
Correlation (r=)0.71	106	243	51	400

Table 7 illustrates the correlation of demographic characteristics of sample to knowledge about epilepsy: age had weak correlation (r=0.3) while marital status had moderate correlation (r=5.6). Monthly income had high correlation to knowledge (r=0.68) and also the educational level (r=0.71).

Table 8: shows the correlation between sample demographical data and attitudes

Age	**Overall attitudes**			**Total**
	Negative	**Neutral**	**Positive**	
16-26	8	7	39	54
27-37	15	20	78	113
38-48	12	25	98	135
49-59	7	23	35	65
60-70	3	9	21	33
Correlation (r=)0.36	45	84	271	400
Marital status	**Negative**	**Neutral**	**Positive**	
Married	39	66	213	318
Divorce	0	4	10	14
Widow	2	9	19	30
Separated	4	5	29	38
Correlation (r=)0.47	45	84	271	400
Monthly Income	**Negative**	**Neutral**	**Positive**	
Satisfied	17	31	116	164
Satisfied to some extent	23	29	122	174
Unsatisfied	5	24	33	62
Correlation (r=)0.69	45	84	271	400

Education level				
	Negative	Neutral	Positive	
No read, No write	4	9	8	21
Primary	11	21	51	83
Secondary	18	32	99	149
Bachelor and above	12	22	113	147
Correlation (r=)0.58	45	84	271	400

Table 8 illustrates the correlation of demographic characteristics of sample to attitudes towards epilepsy: age had weak correlation (r=3.6) and also the marital status (r=0.47). Monthly income had high correlation to attitudes (r=0.69) and also the educational level (r=0.58).

DISCUSSION:

Awareness, knowledge and attitudes towards PWE vary between different communities in different countries and sometimes in the same country [9]. This study is a trial to obtain information about the awareness and knowledge of some families with epileptic members in Baghdad and its suburbs towards epilepsy. Epilepsy is subject to misconceptions, stigmatization, and social misunderstanding, ultimately affecting the QOL of PWE more than the disease itself [10].

Enhanced awareness and knowledge among public would lessen fears and minimize social discrimination against epileptics in the society. Lack of knowledge about epilepsy has been considered a significant determinant factor in the negative attitudes towards PWE [11]. Furthermore, lack of knowledge about epilepsy is not a local or regional problem; it has been shown in a large part of the population throughout the world [12].

The study was conducted in Baghdad city among families of epileptic patients who were consulting private clinics and public outpatient clinics. Four hundred families were contacted, which can be representative for the target population, although inadequate to represent all the epileptics of Iraq.

The targeted families were contacted in a convenient way while they awaited their turn for the patient to see the physician. The interviewer met them and asked to fill out the questionnaire freely with input of caregivers as per the need. The study allowed a free flow of families with different levels of education, ages, and other sociodemographic features.

The caregiver is usually the father (40.5%), followed by mother (32%); this may not reflect the exact situation since families in their consultations to clinics whether private or public are usually accompanied by males mostly the father, while at home the real caregiver is possibly the mother. The majority of families in this study (77.8%) live in urban districts and this possibly is due to geographical reasons since the study was conducted in Baghdad. People in rural areas possibly had some difficulties to consult in the Capital.

The current study showed a relatively low level of awareness for epilepsy where only about 40.5% of families had heard about epilepsy before having an epileptic family member. This is possibly similar to previous studies in Turkey [13], UAE [14], Thailand [15], and Ethiopia [16]; but is apparently lower than the studies performed in KSA (Saudi Arabia) [17], Jordan [18], and Uganda [19].

In spite of this low level of public awareness, and surprisingly, misconceptions and myths were minimally reported in this study. Only 13.5% of families believed in Jinn being the cause of seizures. This is in alignment with results from KSA [17] and Ethiopia [16] and was lower than another study in KSA [20] where 46.5% of respondents chose possession by demons or evil spirits.

Positive attitudes were illustrated with regards to epilepsy stigmatization; the majority of sample families (86.5%) did not feel epilepsy as a stigma; 73.3% of families did not feel embarrassed about being asked about their epileptic children. This is in alignment with recent studies who found improvement in public attitudes towards epilepsy even though levels of knowledge remained fairly static [21-25], and in contrast to studies in Czech Republic [26] and in Austria [27].

As an indicator of hope, only 4.3% of families believed that epilepsy is contagious; this is quite better than a number of studies, in Cameron [28], KSA [29] and almost similar to results from China [21], Jordan [18] and Kuwait [22].

In this study 72.5% of families believed that the epileptic patients cannot marry and 68.3% stated that epileptics cannot have their own children. This is really a very negative attitude towards PWE regarding on the social front, and might be indicative of unfavorable circumstances of social lives of PWE in Baghdad and the vicinity. These results are worse than a lot of studies in the region, which showed better attitudes towards the aspects of marriage and reproduction [18, 21, 30].

A significant factor affecting the public acceptance to epileptics' marriage and reproduction is the concern that epilepsy is inherited [17, 18]; only 26.3% of families in this study believed that epilepsy is not hereditary. An explanation for the negative attitudes towards marriage of epileptic patients in this study is that it included families with epileptic members. These families may have suffered from issues such as 'divorce' or 'separation' among PWE.

With respect to educational level, participants with higher education among families in our study possessed significantly better attitude and knowledge compared to those with lower educational level; this is in alignment with other studies which stated that a higher level of education correlated positively with awareness, knowledge and attitudes concerning epilepsy [31-34].

With reference to this study about 36.5% of families stated to have special schools for their epileptic children whereas 47% of families believed that ordinary schools are fair. This is supported by previous studies which illustrate that ordinary schools are useful for social mingling of epileptics [17, 20].

In this study, a considerable number of families (49.3) of the sample agreed that an epileptic patient should have an employment opportunity like normal candidates. This is in alignment with a KSA study [20] and better than the results of relevant studies done in KSA [17] and Jordan [18], but lower than the study of UAE [14].

However no significant effects were proved in this study for age and occupation in contrast to marital status and monthly income; each sociodemographic feature may be addressed as a predictor for only single aspects of either knowledge or attitude [20].

In terms of monthly income, participants with higher monthly income possessed better knowledge and attitudes than those with lower income who showed deficient knowledge and more negative attitudes. Persons with lower income probably have less access to information concerning epilepsy; this is suppor-

ted by previous studies in China [35] Taiwan [32] and India [36, 37].

In support of our findings, it has been demonstrated that higher educational level and socioeconomic status were associated with greater knowledge and more favorable attitudes towards epilepsy [34, 38-41].

Concerning first-aid knowledge, only 30.5% of the sample turn the patient on their side, and only 21.5% open the tie and belt while 72.3% would try to resist the limb movements of seizing patients. This showed poor knowledge and negative attitudes towards an ongoing seizure. This is in contrast to other studies from Turkey [23] and UK [24] which stated that persons who had witnessed one seizure attack or more, were more acquainted with the first-aid management of seizing patients, and that seeing seizures in public would improve knowledge regarding first-aid procedures.

In terms of treatment, only 22.3% of families in this study stated that herbs and non-medical therapy are useful for treating epilepsy. The majority believed that modern medicine is the best choice for epilepsy management, and about 35.8% believed that epilepsy would be cured completely. This is quite better than the studies done elsewhere, KSA [17, 42] Ethiopia [16] UAE [14] and Uganda [19] while is in alignment with the study of Laos [43] which indicated the preference of modern medicine. On contrary the Chinese in Malaysia preferred alternative medicine for managing epilepsy [33], and people in Myanmar as well [44]. Alternative medicine such as herbal medicine and dietary supplements may have disadvantages in patients with epilepsy as stated by a study on Turkish children [45]. They may also have adverse effects, interact with ASD or possess contraindications [46].

CONCLUSIONS:

The results of the present study show that sample families had a low level of awareness for epilepsy before their patients were affected and diagnosed. They have a positive attitude towards most aspects of epilepsy like getting an appropriate occupation and access to learning facilities and ordinary schooling. They mostly underlined physical causes of epilepsy and rejected supernatural powers and demon possession. Negative attitudes were illustrated towards the aspects of marriage and reproduction of epileptic patients in spite of the highly positive attitudes towards stigmatization. It has been demonstrated that higher educational level and socioeconomic status were associated with greater knowledge and more favorable attitudes towards epilepsy whereas no significant relation was found with respect to age and occupation.

Family members require more education about epilepsy and more training on first aid procedures through community education programs to increase awareness and knowledge about epilepsy.

Conflicts of interest: The authors declare that they have no conflicts of interest.

Authors' contributions: All the authors developed the proposal, collected the data of the study, analyzed and wrote the thesis. They approved the final manuscript and agreed to be accountable for all aspects of the work.

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