## Parental Knowledge, Attitudes, and Practice toward their Epileptic Children, Baghdad, Iraq 2022

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#### Abstract:

**Background:** Epilepsy is one of the most common neurological disorders. People who know less about epilepsy tend to have negative ideas about the disease. KAP of parents on epilepsy is crucial, especially to children below 13, as the child in this stage mostly depends on parents to get the answers to their concerns. Still, the over-protection from their families will create insecurity and reduce their self-esteem when they grow older.

Received: April. 2023 Revised: Jun., 2023 Accepted: Jul. 2023 Published: Jan 2024

**Objectives:** To assess the knowledge, attitude, and practice (KAP) and measure their association with sociodemographic characteristics.

**Methods:** A cross-sectional study involved 107 parents with children who were diagnosed and received treatment for epilepsy. This study was conducted in the consultation clinics in the Children Welfare Teaching Hospital, Medical City in Baghdad-Iraq, from January through July 2022. A questionnaire was developed and filled out through direct interviews with the participants. The questionnaire was composed of five parts. The first part included primary sociodemographic data. The second part concerns the particular child's basic characteristics and epilepsy history. The third part concerns the parents' knowledge about child epilepsy. The fourth part concerns parents' attitudes toward children with epilepsy. The fifth part is concerned with the practice of parents toward child epilepsy.

**Results:** Good knowledge, attitude, and practices were seen among 61 (57.0%), 70 (65.4%), and 90 (84.1%) parents, respectively. Good parents' knowledge of epilepsy was significantly associated with higher education (college) and with fewer family

Members (<5), respectively. In addition, a good parents' attitude towards epilepsy was significantly associated with higher education (college).

**Conclusion:** About half of the parents have good knowledge, two-thirds have a good attitude, and most have good practices regarding epilepsy.

Keywords: Attitude; Epilepsy; Knowledge; Parents; Practice.

#### Introduction

Epilepsy is a neurological disorder viewed as a disease with dire social consequences. Epilepsy affects children directly by influencing social, emotional, and overall family functioning, and it is the most difficult in families where younger children are involved and those with single parents. Religious and cultural beliefs will affect treatment options and parents' compliance levels.

Many of these beliefs in developing countries will negatively impact patients (1, 4). In some countries, patients with epilepsy are considered abnormal, and people think of the disease as shameful and contagious. They avoid these patients so that they will be treated differently regarding education, jobs, and marriage. Some families try to protect their child by preventing her/him from going to school and depriving her/him of social activities (2, 5, 6). The care of the epileptic child is challenging, as it puts a great responsibility on the family, and increases the risk of depression among the family members. Studies have shown that epileptic patients and their families do not have enough information about epilepsy, such as the types of seizures, the cause, and the side effects of medications (5, 7)

A better understanding of the families of epilepsy makes better compliance and results in avoiding complications affecting children's behavioral and psychological outcomes (8).

Knowledge, Attitude, Practice (KAP) surveys are valuable methods to collect data from a population about a specific topic using a structured, standardized questionnaire and help to manage their information, actions, and beliefs about that topic (9). KAP of parents on epilepsy is crucial, especially to children below 13 years of age, as the child in this stage mostly depends on parents to get the answers to their concerns. Still, the over-protection from their families will create insecurity and reduce their self-esteem when they grow older. In Iraq, limited studies describe the parents' knowledge, attitude, and practice toward epilepsy. Therefore, this study aims to assess the knowledge, attitude, and practice (KAP)

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toward epilepsy of Iraqi parents having epileptic children attending the Children Welfare Hospital, Medical City Teaching Complex, Baghdad, Iraq, 2022, and measure the association between sociodemographic characteristics of parents with their knowledge, attitude, and practice towards epilepsy.

#### **Patients and Methods**

A cross-sectional study was conducted in the consultation clinics in the Children Welfare Teaching Hospital, Medical City in Baghdad-Iraq, from January through July 2022. Ethical Approvals were obtained from the Institutional Review Board, Letter No. 6 dated 3.1.2022, and verbal consent was obtained from all participants.

The target population was all parents with children (aged up to 18 years) who were diagnosed and have received treatment for epilepsy, attending the Children Welfare Hospital during the assigned period, and who agreed to participate in the study. Parents of children with a febrile fit, parents of children with fit attacks due to other neurological disorders, parents of children still undiagnosed, and family refusal to participate were excluded.

A structured questionnaire filled through direct interviews was developed and reviewed by the faculty members of the department as well as a consultant in neuro-pediatrics. The questionnaire was composed of five parts:

The first part included primary sociodemographic data about the family, such as age, gender, parent's education level, and the number of family members. The second part is concerned with the particular child's basic characteristics and epilepsy history, which includes the child's age, sex, order in the family, cause of the disease as reported by the family, and any report of status epilepticus.

The third part concerns the parents' knowledge about child epilepsy. It included whether the cause of epilepsy is unknown, whether epilepsy is a disorder of the brain, whether epilepsy is a hereditary disease, whether epilepsy is a contagious disease, whether all the affected children have the same symptoms, whether children with epilepsy have a lower IQ, epilepsy could be treated with medications, can epilepsy be treated with surgery.

The fourth part is concerned with the attitude of parents toward child epilepsy. It included whether an epileptic person could live equally with others in society, whether an epileptic person can perform daily physical activities, whether epilepsy is an obstacle to the good life, whether the intelligence of epileptic persons is lower than average persons, whether epileptic patients should work in specific jobs and with each other, a child with epilepsy should take a lifelong treatment, patients with epilepsy should not get married.

The fifth part is concerned with the practice of parents toward child epilepsy. It consisted of two questions, the first one was "What will you do if your child is getting an epileptic attack?" and the second one was "What will you do to stop epileptic attacks from happening to your child?" All questions having two possible answers were given either 1 point for a correct response or zero points for a wrong or uncertain response. The answers with a score of less than 50% were considered poor, 50-75% were considered fair, and the answers above 75% were considered good.

A pilot study was done on a sample of 10 caregivers of epileptic children to assess the clarity of the questions and any modifications needed and to estimate the time required to fill in the questionnaire. The parents who participated in the pilot study were excluded from the primary research. No significant changes were made after the pilot study.

#### Statistical analysis

Microsoft Excel 2010 and IBM SPSS version 28 were used for data entry. Data description was presented as tables. The association between categorical variables was tested using the chi-square test. A p-value of <0.05 was considered significant.

#### Results

One hundred seven parents of children with epilepsy participated in this study. Their mean age was 34.6  $\pm$ 8.10 years. There were no cases over the age of 12 years. Of all parents, 41 (38.3%) had primary school education or were illiterate, and 38 (35.5%) were college graduates. The parents with more than five family members were 61 (57.0%), table 1. The mean age of the epileptic children was 4.4  $\pm$ 3.19 years; 51 (47.7%) were in the age group >1.5-5 years, and 54 (50.5%) were females. Thirty children (28%) ranked first in their family. As per the presumed cause

ranked first in their family. As per the presumed cause of the disease, 70 parents (65.4%) responded as unknown, table 1.

Characteristics of parents		N (107) %		Characteristic of children		N (107)	%
Age of parents	20-39	76	71.0	Age of child	≤1.5	19	17.8
(years)	40-59	31	29.0	(years)	>1.5-5	51	47.7
Gender	Male	37	34.6	_	6-12	37	34.6
	Female	70	65.4	Sex	Male	53	49.5
Parents' education	≤ Primary	41	38.3	_	Female	54	50.5
	Secondary	28	26.2	Order of the	First	30	28
	College	38	35.5	child in the	Second	37	34.6
Family members	<5	46	43	family	Third	19	17.8
	≥5	61	57		Fourth +	21	19.6
Fathers' occupation	Employed	95	88.8	Cause of the disease as	Fever	26	24.3
	Unemployed/ retired	12	11.2		Brain	11	10.3
Mothers' occupation	Employed	8	7.5	reported by the family	Unknown	70	65.4
	Unemployed/ retired	99	92.5	Any report of s	tatus epilepticus	22	20.6
Parents' Marital	Together	99	92.5	_			
status	Divorced/ Widowed	8	7.5				

Regarding the knowledge of the parents about child epilepsy, 106 parents (99.1%) correctly answered the question (Is epilepsy a contagious disease), and 32 parents (29.9%) correctly answered the question (Can epilepsy be treated with surgery). As for attitude, the highest correct answer was for the question (Should epileptic patients work in specific jobs and with each other?) 93 parents (86.9%), and the lowest correct answer was for the question (Should a child with epilepsy take a lifelong treatment?) five parents (4.7%). Regarding practices towards epilepsy among parents of epileptic children, 90 parents (84.1%) selected the correct answer for the question (What will you do if your child is getting an epileptic attack?). All parents chose the correct answer to the question (What will you do to stop epileptic seizures from happening to your child?).

Table 2: Responses of the parents of epileptic children to the KAP questions

Questions of knowledge	Yes	s No		I do not know		
	Ν	%	Ν	%	Ν	%
Is the cause of epilepsy unknown	34	31.8	68	63.6	5	4.7
Is epilepsy a disorder of the brain	99	92.5	1	0.9	7	6.5
Is epilepsy a hereditary disease	6	5.6	100	93.5	1	0.9
Is epilepsy a contagious disease	0	0	106	99.1	1	0.9
Do all the affected children have the same symptoms	15	14.0	82	76.6	10	9.3
Do children with epilepsy have lower IQ	33	30.8	71	66.4	3	2.8
Could epilepsy be treated with medications	79	73.8	14	13.1	14	13.1
Can epilepsy be treated with surgery	32	29.9	19	17.8	56	52.3
Questions of attitude	Yes		No		I do not know	
	Ν	%	N	%	Ν	%
An epileptic person lives equally with others in society.	71	66.4	34	31.8	2	1.9
An epileptic person performs daily physical activities.	69	64.5	37	34.6	1	0.9
Epilepsy is an obstacle to the good life.	37	34.6	68	63.6	2	1.9
The intelligence of epileptic persons is lower than average persons.		30.8	72	67.3	2	1.9
epileptic patients work in particular jobs and with each other.	11	10.3	93	86.9	3	2.8
A child with epilepsy takes lifelong treatment.		66.4	5	4.7	31	29.0
A patient with epilepsy should not get married.	11	10.3	92	86.0	4	3.7
Questions of practices					Ν	%
What will you do if your child gets an epileptic attack?		I will call an ambulance			0	0
		I will give him the first aid I do not know what to do			90	84.1
					17	15.9
What will you do to stop epileptic attacks from happening to your child?		Use herbal medicine			0	0
		Follow up with a doctor			107	100.
		No need for	0	0		

A good attitude towards epilepsy among parents of epileptic children was significantly associated with higher education (college) (p=0.015). There were no statistically significant associations with other characteristics (p>0.05), table 3.

# Table (2): KAP scores towards epilepsy among parents of epileptic children

KAP Scores	Poor A		Av	erage	Good	
	Ν	%	Ν	%	Ν	%
Knowledge score	6	5.6	40	37.4	61	57.0
Attitude score	32	29.9	5	4.7	70	65.4
Practices score	0	0.0	17	15.9	90	84.1

Good knowledge of epilepsy among parents of epileptic children was significantly associated with higher education (college) and with fewer family members (<5) (p<0.001 and p=0.0002, respectively). There were no statistically significant associations with other characteristics (p>0.05), table 4

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Table (4): Association between Sociodemographic features of parents of epileptic children and their knowledge towards epilepsy

Sociodemographic characteristics of parents			Knowledge					
		Pe	Poor		Average		Good	
		N	%	Ν	%	Ν	%	
Parents' age	20-39	6	7.9	28	36.8	42	55.3	0.27
group (years)	40-59	0	0	12	38.7	19	61.3	
Parents' gender	Male	1	2.7	13	35.1	23	62.2	0.55
	Female	5	7.1	27	38.6	38	54.3	
Parents' education	≤Primary school	6	14.6	27	65.9	8	19.5	< 0.001*
	Secondary school	0	0	8	28.6	20	71.4	
	College	0	0	5	13.2	33	86.8	
Family members	<5	1	2.2	10	21.7	35	76.1	0.002*
	≥5	5	8.2	30	49.2	26	42.6	
Fathers' employment	Employed	6	6.3	34	35.8	55	57.9	0.48
	Unemployed/retired	0	0	6	50	6	50	
Mothers' employment	Employed	0	0	3	37.5	5	62.5	0.76
	Housewife/retired	6	6.1	37	37.4	56	56.6	
Parents' Marital status	Together	6	6.1	39	39.4	54	54.5	0.19
	Divorced/widowed	0	0	1	12.5	7	87.5	

#### **Discussion:**

The mean age and the distribution of the parents by age group are similar to those reported by Frank-Briggs & Alikor in Nigeria (10). There were more mothers interviewed than fathers in the current study, which may be related to cultural issues where the mothers usually accompany the sick child during hospital visits. This result is different from those of a study from Nigeria and that reported by Rani & Thomas in India where two-thirds of participants were fathers. Shaju et al from India found approximate percentages of both parents with slightly higher males than females (10-12).

The finding of five or more family members in the current study is close to the average family member of the Iraqi family (13).

The proportion of males and females in the current study was almost equal. Generally, the prevalence of epilepsy is higher in males, but certain types of epilepsy, like juvenile myoclonic epilepsy and absence epilepsy, are more prevalent in females. The current study did not highlight the type of epilepsy that may affect the findings in this study (14, 15). Most parents responded that the possible cause of their children's disease was unknown. Many traditional societies link epilepsy to natural and supernatural origins, such as India, Morocco, and Iraq (16-18). One-third of parents believed that the illness had a cause, a finding consistent with Neyaz et al. study in Saudi Arabia. In developing communities, there are many false beliefs and misconceptions regarding epilepsy in the general population and among families of epileptic patients (19, 20). Knowledge of parents revealed that one-third of parents believed the illness had a cause; most thought epilepsy was a mental disorder that didn't match Masri et al. study in Jordan; who reported that 48.4% of families with epileptic children thought that epilepsy was due to a mental disorder. Over half of the parents had a misconception regarding the symptoms of epilepsy and its IQ, which could be

related to a higher association of co-morbidities and developmental delay in epileptic patients that may cause this misconception (21, 22).

About two-thirds of respondents believe in medication as an effective measure for treatment, which is consistent with Shaju et al. study in India. While Zainy et al. study in Jeddah, Saudi Arabia reported that one-third of respondents believed that epilepsy can be treated surgically, reflecting poor knowledge of the surgical role in treatment (12, 23).

A positive attitude toward epileptic children regarding their living equally with others and performing daily activities was also seen in a study by Hassan et al. in Abha City (8). The current study also showed that parents of epileptic children disagree with the assumption that epileptic children should work in specific jobs with each other and encouraged the marriage of epileptic children in the future, which disagrees with Dessalegen in Ethiopia regarding working with other epileptic children (24). Alsudairy et al., in Jeddah, Saudi Arabia, reported that most respondents had negative attitudes toward the ability of epileptic children to have a normal life (25). The parent's negative attitude about epilepsy appeared to be motivated by cultural belief that epilepsy was genetically inherited and brought on by demons or mental diseases.

Compared to Hassan et al. study in Abha City, most participating parents would administer first aid and follow up with a doctor to prevent the repetition of the seizures, indicating a good practice for the participant parents. Improved knowledge can positively impact parents' practice of performing the child's first aid (26).

Over half of the participants had good knowledge and attitude, and most participants had good practice, which is higher than other studies conducted in Iraq and KSA. Alsudairy et al., in Jeddah, Saudi Arabia, reported a poor KAP score. The difference can be related to inadequate medical consultation, insufficient safety measures taken by parents during the convulsion, and lack of training (13, 23, 26).

In consistence with other studies, the knowledge score increased with increased academic level. The higher academic level can give the parent better information about the disease, away from the cultural myths. Even in low-income nations, parents of children with epilepsy report feeling less stigmatized if they had a higher degree of education (27-30).

A small family size (<5 members) was associated with good knowledge, also demonstrated by Al-Zweihary et al. in Saudi Arabia. A smaller-size family helps the parent to focus on the epileptic child and gain more information about the condition. Potential confounding with parents' education is possible as educated parents usually have fewer children (31).

**Conclusion:** This study highlighted the effect of some sociodemographic characteristics of parents on their good knowledge, attitude, and practice toward epilepsy.

#### Authors Declaration:

Conflicts of Interest: None.

We hereby confirm that all the Figures and Tables in the manuscript are mine/ ours. Besides, the Figures and images, which are not mine /ours, have been given permission for re-publication and attached to manuscript. Authors sign on ethical the consideration's Approval-Ethical Clearance: The project was approved by the local ethical committee (Medical Research Ethics Committee of Children Welfare Teaching Hospital, Medical City in Baghdad-Iraq, and the Center of Training and Human Resources Development in College of Medicine/University of Baghdad).

#### Author Contributions:

Faris H Lami is an Editor in Chief for the journal but did not participate in the peer review process other than as an author. The authors declare no other conflict of interest.

Study conception & design: (Faris H Lami). Literature search: (Sama A. AlQaisi). Data acquisition: (Sama A. AlQaisi). Data analysis & interpretation: (Faris H Lami). Manuscript preparation: (Sama A. AlQaisi). Manuscript editing & review: (Faris H Lami & Eman M Ali).

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How to cite this Article

Al-Kaisi SA, Lami FH, Ali EM. Parental Knowledge, Attitudes, and Practice toward their Epileptic Children, Baghdad, Iraq 2022. JfacMedBagdad. ;65(4). <u>https://iqimc.uobaghdad.edu.iq/index.php/19JFacMedBag</u> <u>hdad36/article/view/2112</u>.

### المعرفة والمواقف والممارسات تجاه الصرع بين آباء وأمهات الأطفال المصابين بالصرع في بغداد، العراق 2022

سما عبد الحميد القيسي<sup>1</sup>، فارس حسن اللامي<sup>1</sup>، ايمان محمد علي<sup>2</sup> أ فرع طب الأسرة و المجتمع، كلية الطب، جامعة بغداد، بغداد، العراق. 2 الكلية الملكية في ايرلندا للأطباء الممارسين، ، مركز طب الاسرة وود بروك، إيرلندا

#### الملخص

**الخلفية:** الصرع هو واحد من أكثر الاضطرابات العصبية شيوعًا. الأشخاص الذين يعرفون القليل عن الصرع يميلون إلى امتلاك أفكار سلبية حول المرض. معرفة وتصرف الآباء تجاه الصرع أمر بالغ الأهمية، خاصة بالنسبة للأطفال دون سن 13 عامًا، حيث يعتمد الطفل في هذه المرحلة بشكل كبير على الآباء للحصول على إجابات لاستفساراتهم. ومع ذلك، فإن حماية الأطفال بشكل زائد من قبل عائلاتهم قد تؤدي إلى إحساسهم بعدم الأمان وتقليل تقدير هم لأنفسهم عندما يكبرون .

ا**لأهداف:** تقديرُ المعرفة والمواقف والتصرف (KAP) لدى الآباء وقياس علاقتها بالسمات الاجتماعية والديمو غرافية.

الطرق: دراسة مستعرضة شملت 107 أباء لديهم أطفال تم تشخيصهم وتلقوا علاجًا للصرع. تمت هذه الدراسة في عيادات الاستشارية في مستشفى حماية الطفل التعليمي، مدينة الطب في بغداد، العراق، من يناير إلى يوليو 2022. تم تطوير استبيان وملئه من خلال مقابلات مباشرة مع المشاركين. يتألف الاستبيان من خمسة أجزاء. الجزء الأول يتضمن بيانات ديمو غرافية أولية. الجزء الثاني يتعلق بالسمات الأساسية للطفل وتاريخ الصرع. الجزء الثالث يتعلق بمعرفة الأباء حول الصرع عند الأطفال. الجزء الرابع يتعلق بمواقف الآباء تجاه الأطفال المصابين بالصرع. الجزء الخامس يتعامل مع تصرفات الأباء تجاه الصرع عند الأطفال. الجزء الرابع يتعلق بمواقف الآباء تجاه الأطفال المصابين بالصرع. الجزء الخامس يتعامل مع

النتائج: وجد أن 61 (57.0%) من الأباء يمتلكون معرفة جيدة، و70 (65.4%) يمتلكون مواقف جيدة، و90 (84.1%) يمتلكون تصرفات جيدة تجاه الصرع. كانت معرفة الأباء الجيدة بالصرع مرتبطة بشكل كبير بالتعليم العالي (الكلية) و عدد أقل من أفراد الأسرة 0.001<P=) (5>) و (2000.9= على التوالي. بالإضافة إلى ذلك، كانت مواقف الأباء الجيدة تجاه الصرع مرتبطة بشكل كبير بالتعليم العالي.

**الاستنتاج:** حوالي نصف الأباء لديهم معرفة جيدة، ونصفين آخرين لديهم مواقف جيدة، ومعظمهم لديهم تصّرفات جيدة تجاه الصرع . **الكلمات الرئيسية:** مواقف، صرع، معرفة، آباء، تصرفات