



## Parental knowledge and attitudes towards epilepsy –A study from Jordan



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### ABSTRACT

**Purpose:** To explore the knowledge, attitudes and behaviors of parents whose children were diagnosed with epilepsy.

**Methods:** Cross-sectional questionnaire based study of parents who accompanied their children with epilepsy to the child neurology clinics at three university hospitals in Jordan.

**Results:** Most parents (427, 90.3%) knew that epilepsy is not related to a psychiatric disease. Approximately half of the parents (245, 51.8%) used the internet as their source of knowledge, and most used Arabic websites. Searching the word epilepsy was rarely used (51, 10.8%).

Most of the parents (428, 90.5%) were not restricting their children from watching TV or from using the computer (358, 75.5%). However, many parents (280, 59.2%) were restricting them from participating in sports.

Parents had negative attitudes towards epilepsy; 189 (40.0%) thought that epileptic children can have normal intelligence, and 292 (61.7%) thought that they can continue into higher education. Greater parental knowledge of epilepsy was found to be correlated with the parental education level ( $p < 0.05$ ). Positive attitudes and behaviors towards epilepsy were found to be correlated with a higher parental education level, control of epilepsy, an absence of associated co morbidities, a higher income and internet use ( $p < 0.05$ ).

**Conclusion:** This study sheds an important light on the current knowledge status and attitudes of parents of children with epilepsy, and is an invaluable tool for tailoring the delivery of information and support resources for families in our region.

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## 1. Introduction

Over the last few years, there has been increasing awareness regarding the effect having a child with epilepsy has on parents, and the reciprocal effect of parental knowledge and attitudes about epilepsy on the affected child [1,2]. Furthermore, parental attitudes

about epilepsy were as significantly related to child outcome as seizure history and epilepsy duration [3]. Poor child psychosocial/behavioral outcome was associated with exaggerated fears and protective attitudes in parents [3]. In addition, a high proportion of parents continue to have information and support needs that remain significantly high during the first two years after diagnosis [4].

Studies addressing parental knowledge about epilepsy have consistently documented a knowledge gap [5,6,7]. In the developing world, this knowledge gap will only exacerbate the already significant and well documented treatment gap [8,9]. In the systematic review by Mbuba et al 2008 [10], cultural beliefs and individual perceptions greatly influenced treatment seeking

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behavior, and it was shown that some attributed causes of the treatment gap in developing countries could be addressed through educational interventions [10].

Public awareness and attitudes towards epilepsy vary across different cultures, and developing countries are not a homogenous entity; discrepancies in attitudes and source of knowledge have been previously described [11–15].

Previous studies have shown that the general Jordanian population has poor knowledge and negative attitudes towards epilepsy [16,17]. However, knowledge and attitudes among parents of children with epilepsy in Jordan have not been studied before. We assume that exploring the specific needs of parents about epilepsy would help us understand their needs. Understanding parental needs may help us as clinicians to deliver better knowledge to them which may influence the overall quality of life of the whole family.

Thus, this study aimed to explore parental knowledge and attitudes towards epilepsy in Jordan, including the exploration of parental resources and preferred methods of obtaining further information about this diagnosis. This study would be a vital first step towards the implementation of effective educational interventions tailored to the needs of these parents as a target population.

## 2. Patients and methods

This prospective, cross-sectional study was carried out at the pediatric neurology clinics of three university hospitals in Jordan: Jordan University Hospital, King Abdullah University Hospital, and Al Karak Hospital from January 2015 to December 2015. Jordan university hospital is a tertiary care hospital located in Amman, and is a central referral hospital. King Abdullah University Hospital is a tertiary referral hospital for the northern region of Jordan, and Al Karak hospital is a referral hospital for the Southern region of Jordan.

### 2.1. Inclusion criteria

Parents were recruited through the outpatient neurology clinics. All parents of children younger than 18 years of age with a diagnosis of epilepsy for a minimum of six months were approached for inclusion in the study. Only parents were targeted in this study, other caregivers accompanying the child were excluded.

### 2.2. The questionnaire

After obtaining informed consent, a structured questionnaire was administered to the accompanying parent by trained research assistants.

The questionnaire was modified from international questionnaires that were previously used to assess parental knowledge and attitudes towards epilepsy [18,19,20]. The questionnaire was translated into Arabic then back translated to make sure the translation was accurate. A pilot study including 10 parents was conducted in each center before the start of the study. Assessment of the inter-rater reliability of the resultant questionnaire was carried out and only minor modifications were needed.

Culturally relevant questions were also added, such as questions regarding seeking locally available complementary and alternative medicine, and those regarding superstitious beliefs about causality of epilepsy.

The questionnaire consisted of 4 sections: Parental socio-demographic characteristics, patient demographic and clinical characteristics, parental knowledge about epilepsy including sources of knowledge and management of an acute seizure, and

general parental attitudes and behaviors towards children with epilepsy.

The knowledge section consisted of 14 questions used for scoring, with each correct answer awarded one point, knowledge scores ranged from 0 to 14.

The attitudes and behaviors were included in one section which consisted of 15 questions. The first 6 questions were used for scoring, with each correct answer awarded one point. The scoring system was used to determine correlations between independent factors and parental knowledge, attitudes and behaviors.

Questions included in scoring were related to restriction of children's activities (watching TV, using the computer, restricting participation in sports), and questions related to intelligence, education and employment opportunities. The other questions were related to challenges for parents including dealing with the seizures, and medications, in addition to questions related to stigma of epilepsy.

### 2.3. Data analysis and statistical methods

#### 2.3.1. Factors related to parental knowledge, attitudes, and behaviors towards epilepsy

We studied the effect of several factors on parental knowledge and attitudes towards epilepsy. Parental factors included the sex of interviewed parent, educational level of the interviewed parent, family income and positive family history of epilepsy. Factors related to the children and their epilepsy included the child's age at the onset of epilepsy, epilepsy control, (we considered epilepsy as controlled if there were no seizures in the past year), and associated co morbidities including developmental delays, spasticity, school difficulties, and speech delay.

Statistical analysis was performed using the Statistical Package for Social Sciences version 17 (SPSS Inc., Chicago, IL, USA). The frequencies, proportions and comparisons of means using a *t*-test or analysis of variance (ANOVA) were applied wherever appropriate. Differences were considered statistically significant if  $p < 0.05$ .

The study was approved by the scientific committee of the faculty of medicine, and the IRB and ethical committees of Jordan university hospital.

## 3. Results

A total of 473 parents were included; 216 (45.7%) were from Jordan University hospital, 123(26%) were from King Abdulla University hospital, and 134(28.3%) were from AL Karak hospital. The major three governorates were represented in this sample; 127 (26.8%) parents resided in Amman, 82(17.3%) resided in Irbid, and 118 (24.9%) resided in Al karak. The rest of the parents resided in the other governorates, including Zarqua, Aquaba, Maan, and Tafleeh.

### 3.1. Demographics and epilepsy characteristics

Mothers commonly accompanied their children (315, 66.6%). The monthly income of the families was equal to or less than 500 Jordanian dinar (715 dollars) in approximately three-quarters of the sample (348,73.6%). Most families (400, 84.6%) had medical insurance for their child. In Jordan, all children below 6 years of age have medical insurance and all children(0–18 years) with chronic illnesses have access to medical insurance.

Parental education lower than and up to the high school level was reported for 281 (59.4%) parents, college and university level education was reported for 192 (40.6%) parents, which is ongoing with the high (95%) literacy rate in Jordan.

A positive history of epilepsy was present in 136 (28.8%) of the families, (Table 1 summarizes the demographics of the families).

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