Knowledge and attitudes towards epilepsy in Saudi families

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

Taibah University, KSA

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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 Almunawarawah, 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 participating 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: Taibah University, KSA. E-mail: h-neyaz@hotmail.com (H.A. Neyaz)

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Background

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.1–3 Epileptic seizures are generated from excessive and abnormal cortical nerve cell activity in the brain.4 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 Common examples of 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 Adequate education is the cornerstone 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 (AM) 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 difficult-to-understand questions were modified appropriately. After final revision, the questionnaire was printed in a clear form.

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 allow for multiple responses.

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 ± 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

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
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