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Parent's Knowledge and Attitudes towards Children with Epilepsy

Lama E Zaini, Dania M Atteyah, Wala'aM Aldisi, Hanadi A Abdulkarim, Rawia F Al-helo, Haneen A Al-hilali and Mohammed M Jan*

Department of Pediatrics, Faculty of Medicine, King Abdulaziz University, Jeddah, Kingdom of Saudi Arabia

Abstract

Background: Parent's attitudes toward children with epilepsy are influenced by the degree of their knowledge. Misinformation and misconceptions should be identified and corrected for optimal care and management. Our objectives were to study the parent's knowledge and attitudes and identify contributing factors to negative attitudes.

Methods: Consecutive parents were included prospectively through the pediatric neurology out-patient clinic of King Abdulaziz University hospital, Jeddah, Kingdom of Saudi Arabia. A structured 40-item questionnaire was designed to examine their demographics, knowledge and attitudes toward children with epilepsy.

Results: A total of 117 parents were interviewed, 57% were mothers. The ages of their epileptic child ranged from 1-16 years (median 6.6), mostly (65%) boys. Although most parents (70%) felt informed about epilepsy and recognized various treatment modalities, many believed that epilepsy is a mental disorder (48%), correlates with evil (44%), and affects the child's intelligence (38%). Up to 53% admitted that they treat their epileptic child differently and avoid upsetting or punishing him/her. This behavior was less likely if they achieved college or university education (p=0.01). Some parents (29%) admitted to using non-medical treatments, usually traditional herbs and religious practices. Those parents were more likely to believe that epilepsy is a mental disease (p=0.002) or correlates with evil (p=0.015).

Conclusions: The level of knowledge and understanding about epilepsy among parents of epileptic children needs improvement. Many parents have significant misconceptions, negative attitudes, and poor parenting practices. Increased awareness and educational programs are needed to help improve the quality of life of these patients and their families.

Keywords: Parent; Knowledge; Attitudes; Child; Pediatric; Epilepsy

Introduction

Epilepsy is one of the most common pediatric neurological disorders [1,2]. A key element of managing these patients and their families is adequate education [2]. Parents of children with epilepsy are at high risk of having anxiety, which correlates significantly with their quality of life [3]. Parents' knowledge about epilepsy is associated with lowered parental anxiety. As well, family activities were less restricted if they were more knowledgeable and they reported less worries about their children [4]. Knowledge about epilepsy is also associated with less perceived stigmatization and social isolation, as well as fewer depressive symptoms and misperceptions [4]. Overall, parent's attitudes toward children with epilepsy are influenced by the degree of knowledge of the condition [5-7]. Therefore, misconceptions and misinformation should be identified and corrected for optimal care and management. Examples include overprotection by preventing the child to go to school, participate in sports, or social activities [8,9]. This can result in problems with adaptation and negative effects on the whole family [10,11].

In our experience, many Saudi families are not properly informed about epilepsy and some are misinformed from unreliable sources. This frequently leads to negative attitudes toward their epileptic child. These issues received limited study in our region. Our objectives were to study their level of knowledge and attitudes and identify correlating and contributing factors to their negative attitudes, which may include their personal and social experiences as well as, their socioeconomic and educational levels.

Methods

Consecutive parents were included prospectively through the pediatric neurology out-patient clinic of King Abdulaziz University hospital, Jeddah, Kingdom of Saudi Arabia. The study sample was collected over a 6 month recruitment period during 2012. Only families of children with established epilepsy were included. A structured 40-item questionnaire was designed to examine the parent's demographics, knowledge and attitudes toward children with epilepsy (Table 1). An assigned coauthor conducted the interviews in a private room and individually assisted the parents to complete the questionnaire during a clinic visit. The study design and questionnaire were approved by King Abdulaziz University hospital ethics committee. Informed consent was obtained before participating in the study.

Data were collected in Excel sheets and statistical analysis was performed using SPSS 17 (SPSS, Inc., Chicago, IL, USA). Descriptive analyses were performed and the variables were examined using chi-square test. Statistical significance will be defined as P values of less than 0.05.

Results

A total of 117 parents were interviewed, 57% were mothers. Most families (77%) were of Saudi nationality and 61% were from the Jeddah area. The mother's ages ranged between 21-50 years (median 32) and the father's ages ranged between 23-59 years (median 39). Most families (59% of mothers and 53% of fathers) had college or university degrees; however, most mothers (73%) were working as full time housewives.

***Corresponding author:** Prof. Mohammed M.S. Jan, Department of Pediatrics, Faculty of Medicine, King AbdulAziz University, P O Box 80215, Jeddah 21589, Kingdom of Saudi Arabia, Tel: 996-2-6401000 (ext. 20208); Mobile: 0505698843; Fax: 996-2-6403975; E-mail: mmjan@kau.edu.sa

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Questionnaire	Positive Answers
Knowledge	
Did you hear about epilepsy before the diagnosis?	70%
Are there non-medical treatments for epilepsy?	59%
Is epilepsy a mental disease?	48%
Does epilepsy correlate with evil?	44%
Could the epilepsy be treated by surgery?	41%
Does epilepsy affect the intelligence of the child?	38%
Could the child with epilepsy be cured?	9%
Is the epilepsy contagious?	2%
Attitudes	
Could the child with the epilepsy achieve allot in his future life?	95%
Do you avoid upsetting your child?	53%
Could the child with the epilepsy achieve allot in his future life?	47%
Could the child with epilepsy get married in the future?	47%
Do you treat your affected child different from his brothers?	44%
Is there discrimination against the child with epilepsy in the society?	42%
Do you avoid punishing your child?	34%
Should the child with epilepsy attend a special school?	22%
Do you consider your child always vulnerable to illness and crises?	9%

Table 1: Summary of the questions regarding the parent's knowledge and attitudes towards childrenwith epilepsy (n=117).

The ages of their epileptic child ranged from 1-16 years (median 6.6), mostly (65%) boys. These children had a variety of seizures; however, 60% had recurrent generalized tonic clonic seizures.

As shown in Table 1, most parents (70%) have heard about epilepsy before the diagnosis of their child, usually from a friend or relative in 46% of cases. Other sources of information included a physician, media, and books. Positive answers to key knowledge and attitude questions are summarized in Table 1. Several misconceptions, negative attitudes, and poor parenting practices were identified. Although these parents felt informed about epilepsy and recognized various treatment modalities, many believed that epilepsy is a mental disorder, correlates with evil, and affects the child's intelligence (Table 1). On the other hand, and although most parents felt that the child can achieve allot in the future, they treated him/her differently and 22% felt that they need to put him/her in a special school. This correlated with the educational state as those with college or university degree were less likely to report that they treat their epileptic child different from other siblings (p=0.01). Most parents (72%) knew what to do in an acute seizure situation, however, 14% mentioned that they will sprinkle water to the face and 4.3% would try to shaking the child or carry him or her around. Some parents (29%) admitted to using non-medical treatments for epilepsy, usually traditional herbs and religious practices. Those parents were more likely to believe that epilepsy is a mental disease (p=0.002) or correlates with evil (p=0.015). No other correlations were found between parent's knowledge and attitudes toward epilepsy with their socio-demographic or economic variables.

Discussion

Our study documented that many parents of children with epilepsy are not well informed and have significant misconceptions, negative attitudes, and poor parenting practices. Although they generally felt informed about epilepsy and recognized various treatment modalities, many believed that epilepsy is a mental disorder, correlates with evil, affects the child's intelligence, and cannot be cured (Table 1). Other authors reported similar doubts in the parent's minds about the cognitive potential of children with epilepsy [12]. They felt that those children are not as bright as "normal" children. In another study, an evil spirit was considered the cause of epilepsy by 27% of the parents [13]. Such misconceptions can have significant negative implications on the medical management with higher risk of non-compliance [14]. In addition, some parents thought that the child should attend a special school, considered the child always vulnerable to illness, and that epilepsy is contagious. These misconceptions have been reported more frequently from developing countries with limited educational practices [15-17]. Another issue was over protection as many parents admitted to treating their epileptic child differently from other siblings and avoided upsetting or punishing him/her. This correlated with their educational levels. Other studies have found an influence of the socio-economic grade on the awareness and interaction with seizures [7]. This practice should be highly discouraged as it predisposes to problems with adaptation, relationship with peers, socialization, and school difficulties.

Up to 29% of parents admitted to using non-medical treatments for epilepsy, usually traditional herbs and religious practices. This is a frequent general practice in our region [18]. We found a correlation with the belief that epilepsy is a mental disease or correlates with evil, which explains why they reverted to these interventions. Finally, many parents felt that the child can achieve allot in the future with the risk of societal discrimination. Most of them knew what to do in an acute seizure situation, however, up to 14% performed unnecessary procedures such as sprinkle water to the face, shake, or carry the child around. We did not encounter other inappropriate or potentially harmful procedures related to mythical concepts that were reported by other authors from developing countries, such as forcing liquids by mouth, pressure over body to restrain convulsive movements, or putting some object to force the teeth open [13].

There are some limitations to our study. Our sample was not large; however, it was representative of children with epilepsy with variable ages and socio-demographic backgrounds. Parent's reporting bias may have affected the results since the questions on their knowledge and attitudes are predisposed to subjective judgments. We tried to overcome this problem by assigning one coauthor to personally assist all parents in completing the questionnaire. Finally, the questionnaire is self-structured and hence has not been used or validated in previous studies.

We conclude that the level of knowledge and understanding among parents of children with epilepsy needs improvement. Many parents have significant misconceptions, negative attitudes, and poor parenting practices. These correlated with their educational levels and had significant implications on the medical management. Therefore, there is a need for improving the degree of knowledge, which will help in improving their attitudes toward epilepsy. Demystification of wrong beliefs will influence the family positively and improve the relationship with their child. This is also true for the general public [3,4]. Therefore, educating the community about epilepsy is also essential. The media, as well as, government authorities should play a major role in increasing the public awareness. Parents, teachers, and school children should be targeted with such educational programs. Increased awareness and public educational campaigns can be successful in filling the gaps, ameliorating misconceptions, and minimizing the social stigma, and ultimately improving the quality of life of the children with epilepsy and their families.

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