

Parents' knowledge and attitudes toward children with epilepsy

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ABSTRACT

الأهداف: دراسة مدى معلومات آباء الأطفال المصابين بمرض الصرع وتحديد أسباب انطباعاتهم السلبية عن مرض الصرع والتعرف على العوامل المشتركة للانطباع السلبي.

الطريقة: دراسة عينة من أمهات الأطفال المراجعين لعيادات أعصاب الأطفال، مستشفى جامعة الملك عبد العزيز، جدة، المملكة العربية السعودية خلال الفترة من فبراير حتى أغسطس 2012م. وقد تم ذلك بواسطة استبيان مقنن ومكون من 40 سؤال عن معلوماتهم الشخصية والاجتماعية ومعلوماتهم وانطباعاتهم عن مرض الصرع.

النتائج: تمت مقابلة 117 من والدي الأطفال المراجعين في فترة الدراسة وقد تم مقابلة الأم في 57% من الاحيان. وقد تراوحت أعمار الأطفال المصابين بالصرع بين 1 إلى 16 عاماً (معدل 6.6) معظمهم من الذكور (65%). ورغم أن معظم الوالدين (70%) كانت لديهم معلومات عن مرض الصرع وتعرفوا على العلاجات المختلفة إلا أن كثيراً منهم اعتقدوا أن الصرع مرض نفسي (48%) أو أن له علاقة بالشيطان (44%) أو أنه يؤثر على ذكاء الطفل المصاب (38%). وقد اعترف 53% من الوالدين أنهم يعاملون طفلهم المصاب بالصرع بصورة مختلفة عن أقرانه ويتفادون ازعاجه أو عقابه. وقد كان هذا السلوك أقل لدى الحاصلين على تعليم جامعي $p=0.01$. وقد اعترف أيضاً بعضهم (29%) أنهم قد سبق أن استخدموا علاجات أخرى مكتملة، بديلة، أو شعبية وكان هذا السلوك أكثر لدى من كان لديهم اعتقاد ان مرض الصرع نفسي $p=0.002$ أو له علاقة بالشيطان $p=0.015$.

خاتمة: مستوى معلومات والدي الأطفال المصابين بمرض الصرع يحتاج تحسين حيث أن كثيراً منهم لديه معلومات خاطئة وانطباعات سلبية وطرق تربية خاطئة. ونوصى بمحاولة زيادة الوعي والتثقيف عن مرض الصرع الذي بدوره سوف يحسن من نوعية حياة هؤلاء الاطفال وعائلاتهم.

Objective: To study parents' knowledge and attitude towards children with epilepsy, and to identify contributing factors to negative attitudes.

Methods: A prospective cross-sectional study including consecutive parents attending the pediatric neurology clinics of King Abdulaziz University Hospital, Jeddah, Saudi Arabia from February to August 2012. A structured 40-item questionnaire was designed to examine their demographics, knowledge, and attitudes.

Results: A total of 117 parents were interviewed, 57% were mothers. The ages of their epileptic children ranged from 1-16 years (median 6.6), mostly boys (65%). Although most parents (70%) felt informed and recognized various treatment modalities, many believed that epilepsy is a mental disorder (48%), correlates with evil (44%), or affects the child's intelligence (38%). Up to 53% admitted to treating their child differently and avoiding upsetting or punishing him/her. This behavior was less likely if they achieved college education ($p=0.01$). Some parents (29%) admitted to using non-medical treatments, usually traditional or 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 among parents of epileptic children needs improvement. Many have significant misconceptions, negative attitudes, and poor parenting practices. Increased awareness and educational programs are needed to improve the quality of life of these families.

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Epilepsy is one of the most common pediatric neurological disorders.^{1,2} A key element in 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 of epilepsy is associated with lowered parental anxiety. Also, family activities are less restricted if they are more knowledgeable, and they reported less worries regarding their children.⁴ Knowledge of epilepsy also leads to less stigmatization, social isolation, and depressive symptoms.⁴ Overall, parents' attitudes toward children with epilepsy are significantly influenced by the depth of their knowledge of the disease.⁵⁻⁷ Therefore, misconceptions and misinformation should be identified and corrected for optimal care and management. Examples include overprotection by preventing the child from going to school, participating in sports, or social activities.^{8,9} This can result in problems with adaptation, and negatively effects the whole family.^{10,11} Other studies also documented doubts in the parents' minds regarding the causes and cognitive effects of epilepsy on their children.¹²⁻¹⁴ Some of these misconceptions have been reported more frequently from developing countries.¹⁵⁻¹⁷ Many families in Saudi Arabia are not properly informed about epilepsy, and some are misinformed from unreliable sources leading to negative attitudes toward their epileptic child. These issues have received limited study in our region. Our objectives were to study parents' level of knowledge and attitudes towards children with epilepsy, and identify correlating and contributing factors to their negative attitudes, which may include their personal and social experiences as well as socioeconomic, and educational levels.

Methods. A cross-sectional study included consecutive parents of children living with epilepsy attending the pediatric neurology outpatient clinics of King Abdulaziz University Hospital, Jeddah, Kingdom of Saudi Arabia. The study sample was collected between February and August 2012. Only families of children with established epilepsy, defined as recurrent unprovoked seizures, were included. A structured

40-item questionnaire was designed to examine the parents' 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 in completing the questionnaire during a clinic visit. King Abdulaziz University Hospital ethics committee approved the study design and questionnaire. Informed consent was obtained from the parents before voluntarily participating in the study.

Data were collected in Excel sheets and statistical analysis was performed using the Statistical Package for Social Sciences version 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 mothers' ages ranged between 21-50 years (median 32) and the fathers' 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. The ages of their epileptic children ranged from 1-16 years (median 6.6), mostly comprising boys (65%). These children had a variety of seizures; however, 60% had recurrent generalized tonic clonic seizures. As shown in Table 1, most parents (70%) had 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). Most parents felt that the child will not achieve a lot in the future, and they treated him/her differently, and 22% felt that they need to put him/her in a special school. This correlated with the educational status as those with college or university degrees 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% reported that they sprinkle water on the face, and 4.3% would try to shake the child or carry him or her around. Some parents (29%) admitted to using non-medical treatments for epilepsy, usually traditional herbs and

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Table 1 - Summary of the questions regarding the parent's knowledge and attitudes toward children with epilepsy (n=117).

Questionnaire	Positive answers (%)
<i>Knowledge</i>	
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 epilepsy be treated by surgery?	41
Does epilepsy affect the intelligence of the child?	38
Could the child with epilepsy be cured?	9
Is epilepsy contagious?	2
<i>Attitudes</i>	
Could the child with epilepsy achieve a lot in his future life?	95
Do you avoid upsetting your child?	53
Could the child with epilepsy get married in the future?	47
Do you treat your affected child differently from his brothers?	44
Is there discrimination against the child with epilepsy in 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

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 parents' knowledge and attitudes to epilepsy and 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 parents' minds regarding 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 a 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.¹⁸ 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.¹⁹ 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 will not achieve a lot in the future; however, many believed that they are at 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 sprinkling water on the face, shaking, or carrying 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 the body to restrain convulsive movements, or placing an object to force the teeth open.¹³

There are some limitations to our study. Our sample was not large enough; however, it was representative of children with epilepsy with variable ages and socio-demographic backgrounds. Parent's reporting bias may have affected the results as the questions on their knowledge, and attitudes are predisposed to subjective judgments. We tried to overcome this problem by assigning one coauthor to 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 to improve the degree of knowledge, which will help in improving their attitudes to 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.²⁰ Therefore, educating the community on epilepsy is also essential. The media, as well as

government authorities should play a major role in increasing public awareness. Such educational programs should target parents, teachers, and school children. 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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