

Childhood Epilepsy: What Parents Know, Believe and Do

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Summary

This was a descriptive study to assess parents' knowledge of epilepsy in their children at the Klinik Pakar Pediatrik in Universiti Kebangsaan Malaysia from 1.1.93-31.6.93. Factors that influence the level of knowledge were examined. Our hypothesis was that the level of knowledge was low and level of education and social factors were important. Fifty consecutive parents were interviewed during the clinic appointments. The questionnaire consisted of 25 questions which had been used in a survey on epilepsy in Australia. In order to cater for the local population the questions were modified by adding new questions pertaining to local situation.

The results showed that 90% (45/50) of parents were unaware of the type of epilepsy their children were suffering from. 50% (25/50) of parents knew the underlying cause of epilepsy of which 32% (8/25) attributed it to brain disease, 8% (2/25) to birth defects and 10% (3/25) to fever. Factors such as duration of epilepsy, parental education and racial differences between Malay and other races (Chinese, Indians) did not reach any statistical significance ($p>0.05$).

80% of patients (30/50) were on monotherapy. However, 90% (45/50) of parents were unaware of their children's medications. 82% of parents (31/50) knew that the anti-convulsants would only control their children's convulsions.

Only 10% (8/50) of parents knew the acute management of seizures. Wrong practices such as inserting spoons (5/50) or massaging their limbs (17/50) during an acute attack were still common. 70% of parents (35/50) attended the follow-up clinics hoping that their children's epilepsy would be cured. Parents with low economic status and of children with duration of epilepsy of less than five years had been coming to the clinic regularly. ($p=0.01$ and $p=0.02$ respectively).

In conclusion, the overall knowledge of these parents was poor. In order to improve the management of epilepsy, it is necessary to educate parents with reading materials and effective educational packages.

Key Words: Epilepsy, Parental knowledge, Education package

Introduction

Epilepsy is a common neurological disorder. The incidence of recurrent unprovoked seizures in children and adolescents ranges between 50-100/100,000. The

highest incidence of epilepsy is in the first year of life. It is four times more prevalent in boys. Individuals with epilepsy experience an unusually higher number of problems in psychosocial functions compared to the general population¹.

Epilepsy is a chronic disorder which may need long life treatment. Full parental support is needed to achieve an optimal treatment and to maintain compliance. The parents' attitudes about the illness itself may influence the course of the illness². Many children outgrow their epilepsy but for those who do not, the affected family must learn to live with the disorder. Some children may be weaned off from the anti-convulsants and others will never be controlled. Parents must recognise and understand how this might affect the individual and be able to help the children instead of pitying them.

This study assessed parents' knowledge of epilepsy in their children. Factors that could influence the level of knowledge were examined. Our hypothesis was that the level of knowledge was low and educational and social factors were important.

Methods

This was a descriptive study of children with epilepsy in the Paediatric Institute Kuala Lumpur from 1.1.93-31.6.93. The study population consisted of epileptic children from six months to 18 years old who were on regular follow-up. Parents of 50 children were interviewed during their clinic visits. Interviews were conducted on a one to one basis by the researcher herself either in Bahasa Malaysia or English whichever the parents were more proficient in. The questionnaire consisted of 25 questions which were adapted from an Australian questionnaire on management of epilepsy with regard to patients' perceptions and expectations³. Questions on acute management of seizures and long term management on anti-convulsants and diary keeping were also included. Analysis was done using Fischer Exact Test as a test of proportion at the level of significance of $p < 0.05$.

Results

From a total of 50 children, 26 (52%) were boys and 24 (48%) were girls. The majority of the children were Malays (22/50) followed by Chinese (11/50) and Indians (13/50) (Table I).

Table II shows the age distribution at diagnosis. It shows that the majority of children were diagnosed as epileptics within the first five years of life.

Table III shows the parental background of these patients. 56% (28/50) of parents had secondary education followed by 30% (15/50) with primary education. College or University educated parents constituted only 6% (3/50). Fifty-two per cent of parents were earning between RM555-RM1000 a month.

With regard to therapy, 60% (30/50) of the children were on monotherapy, 26% (13/50) were on two drugs and 12% (6/50) were on three drugs.

Table I
Racial distribution of epilepsy in Paediatric Institute

Race	No. of cases	Percentage
Malay	22	44%
Chinese	11	22%
Indian	13	26%
Others	4	8%

Table II
Age distribution at diagnosis

Age distribution (years)	No. of cases	Percentage
0-1	21	42%
1-5	22	44%
>5	7	14%

Table III
Levels of education of parents with epileptic children

	No. of cases	Percentage
Primary education	15	30
Secondary education	28	56
College/University	3	6
No education	4	8

Knowledge of epilepsy

A total of 45 parents (90%) were unaware of their children's type of epilepsy. Twenty-five parents (50%) responded to the underlying cause of epilepsy as 'don't know'. Of the remaining who responded positively, 32% (8/25) attributed it to brain disease, 8% (2/25) to birth defects and 12% (3/25) to fever. An epileptic attack was seen as a convulsive episode by 78% (39/50) of parents. 4% (2/50) of parents thought that it was a period of loss of consciousness and 2% (1/50) stated that it was a change of behaviour.

Factors such as duration of epilepsy, economic status, parental education and racial difference did not have any influence on this knowledge. The p-value did not reach any statistical significance. ($p>0.05$)

Investigations

CT scan was performed on 56% (28/50) of the children. Only one parent gave the correct reasons for the CT scan. 92% of parents (46/50) knew that their children had an electroencephalogram performed. Only five parents gave the correct reasons for the procedures performed.

Side effects of medications

Side effects of the drugs were common complaints among the epileptic children in previous studies. Common side effects were drowsiness and hyperactivity. In this study the majority of parents i.e. 68% of them (34/50) mentioned no side effects of the drugs. Interestingly only 18 (36%) of parents were asked by their doctors regarding these side effects.

Treatment

Nineteen (38%) parents believed that anticonvulsants would cure epilepsy. The remaining 62% (31/50) believed that anticonvulsants would only control the convulsions. Forty (80%) parents would not stop their children's medication unless advised by their doctors. Of the remainder who stopped voluntarily, reasons given were advice by friends (2/10), child had been on too many drugs (2/10), the child had no more convulsions (3/10) or parents wanted to try alternative therapy since the convulsions were not controlled (3/10).

Seventeen (34%) parents kept a diary record of the epileptic seizures. In children with epilepsy less than five years duration, a significantly lower proportion of parents kept a diary record. ($p=0.03$). Only eight (10%) parents knew how to manage an acute seizure. Fifteen (14%) parents inserted spoons into the mouth for fear of injury to the tongue, 17 (24%) would try to straighten and massage the patients' limbs. Only three (8%) of parents kept medications at home i.e. per rectal valium for use during an acute attack.

Follow-up

Thirty-five (70%) parents attended the follow-up clinic hoping that their children's epilepsy would be controlled. Five (10%) parents wanted to get as much information about their children's epilepsy. Ten (20%) parents visited the doctor with the intention to know the future of their children in terms of education and future job opportunities.

Discussion

This study showed that knowledge of epilepsy among parents was generally poor. 90% of parents were unaware of their children's type of epilepsy. Although 78% of them recognised a convulsive episode, only 10% of them knew how to manage an acute seizure.

Aspects of knowledge can be subdivided into general information regarding epilepsy, investigative procedures and management of epilepsy with regard to drug therapy and acute seizure management. A very high percentage of parents did not know the type of epilepsy their children were suffering from. An Australian study showed that the Australian public³ had better knowledge of epilepsy. Only 10% of respondents were unsure of the type of epilepsy they were suffering from. In contrast to a study conducted in Ethiopia in Central Africa, 52% of the local respondents did not know the cause of epilepsy. 90% of them did not know what care to be given to persons with epilepsy during an acute seizure⁵.

Among the Malaysian parents their understanding of the term 'epilepsy' was poor. It was equivalent to any seizure disorder. This could be seen where the majority of parents responded to the term epileptic attack as a convulsive episode that they had witnessed

occurring in their children or from information from friends or in the mass media. Explaining the term 'epilepsy' and types of epilepsy would be difficult in the Malaysian context. This is because of the need to translate the word epilepsy into the Malay, Chinese or Indian dialect in which the doctor might not be proficient.

The majority of parents knew the investigations that were performed on their children. However, they failed to understand the reasons for them being done. This could be due to the doctor's failure to explain and to make sure that parents understand the reasons of any procedures performed. Parents failed to understand because of language inadequacy and fear or shyness on the parents' part to admit they did not understand the explanations given. This is further compounded in a busy clinic when little time is spent to explain the child's condition and to make sure that relevant information is put across to parents.

The high percentage of parents not knowing their children's medications is a cause of concern. This was made worse by the failure of doctors to provide parents with a simple written action plan including drug names and dosages. Side effects such as drowsiness and hyperactivity were common. In a survey conducted in

Australia, 71% of the epileptics had information on the nature of the medication and side effects³. As in any other chronic illnesses compliance to medication is very important. Failure to explain the side effects would cause parents to stop medications voluntarily resulting in poor control of seizures.

An acute seizure is a very dramatic event to parents and many parents associate it with death. Although they may have witnessed it many times it may cause panic among them. Wrong practices such as massaging and straightening the limbs are still common. This could be that parents were not aware that their practices were wrong. Doctors too might assume that the parents were able to handle this situation and did not test their knowledge from time to time.

In any chronic illness it is important to educate parents about the illness itself. Reinforcement of knowledge is very important. An educational package may be a solution to it. This should include information on drug therapy, its side effects and particularly in acute management of seizures. This package could be in the form of pamphlets or video cassettes which can be distributed or shown during the clinic sessions. In addition short practical management of an acute seizure should be demonstrated to all parents.

References

1. Kessner JL, Austin RN, DWS Noreen, McDermott RW. Parental behaviour and coping behaviour in families of children with epilepsy. *J Neuroscience Nursing* 1988;20 : 174-9.
2. Brain HS, Raizada N. Parental attitudes towards epilepsy. *Indian Paediatric J* 1992;29 : 1437-90.
3. Wall M, Buchanan N, Lambaird M. The management of epilepsy: patients perceptions and expectations. *J Med Aust* 1988;146 : 473-6.
4. Schidmt D. Summary of the first international workshop on compliance in epilepsy. *Epilepsy Res*: 1988 (Supp 1) : 179-82.
5. Redde Teckle Hellwood, Mckonnei Abbei. Attitudes of rural people in Central Ethiopia towards epilepsy. *Sos Sci Med*: 1991;32 : 203-9.