

A study to assess the knowledge and attitude of parents of children with epilepsy

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Abstract

Objective: The objective was to evaluate the knowledge and attitude of parents of children with epilepsy toward the disease. **Methods:** In this cross-sectional, descriptive study, parents of 60 children with epilepsy from pediatric neurology clinic of All India Institute of Medical Sciences were enrolled. Data on epilepsy were collected using pre-tested and validated self-developed knowledge, belief, and attitude questionnaire ($\alpha=0.85, 0.89$). **Results:** The mean knowledge and attitude scores of parents of the children with epilepsy were 9.82 ± 3.9 (2-22) and 31.25 ± 9.27 (0-40), respectively. Parents of the children with epilepsy had poor 50 (83.3%, scores <60%) to fair knowledge scores (60-70%). Majority of the parents 33 (55%) had excellent attitude ($\geq 80\%$), while 11 (18.3%), 6 (10%), and 10 (16.7%) parents had good, fair, and poor attitude, respectively. Correlation between knowledge and attitude was found to be very weak and negative ($r=-0.039, p=0.77$) with few misconception related to disease and clear idea about the activities to be performed with/without caution. **Conclusion:** There is a need for developing informational booklet and conducting educational sessions on epilepsy for the parents in particular and public in general.

Key words: Attitude, Beliefs, Epilepsy, Knowledge

According to the World Health Organization definition, “a diagnosis of epilepsy is made in the presence of recurring seizures, at least two unprovoked ones.” Approximately 45,000 children under the age of 15 develop epilepsy each year. Population-based studies have reported the prevalence rate of 3.6-4.2/1000 children in developed countries; and approximately double these rates in developing countries [1-5]. The prevalence rates of epilepsy in India are similar to those of developed nations [6]. Beliefs, attitudes, and misconceptions toward the disease still exist, and families do not easily accept the disease and its treatment regimen. These “stigma” and misconceptions are due to lack of information and knowledge toward the disease.

The attitude toward the people with epilepsy is influenced by the degree of knowledge of condition [7-9]. Parents play a major role in decision-making about the treatment of their children and beliefs about health and illness affect their decision regarding the choice of treatment. This information of knowledge of parents might help to get a comprehensive picture of children who are being treated in epilepsy clinics, looking beyond seizure control, and may assist in planning the holistic care, giving special attention to social and psychological impact epilepsy has on these children. The objective of our study was to investigate the knowledge, beliefs, and attitude of parents of children with epilepsy toward the disease, which can contribute to the quality of life (QoL) of these children.

METHODS

This study was conducted in pediatric neurology clinic (OPD) of a tertiary care teaching institution of north India between January and December 2013. Data were collected from parents of 60 children with epilepsy using pretested and validated self-developed knowledge, belief, and attitude questionnaire ($\alpha=0.85, 0.89$). The calculated sample size was 60 on calculation on the basis of mean score of QoL in epilepsy children as 75.5 ± 20.8 [10] with 95% confidence and 5% absolute precision. Structured knowledge questionnaire had total 7-items, each one had further sub-items. The items were related to causes, signs, first aid management of epilepsy (maximum score 25), 16-items were related to the beliefs associated with epilepsy, and activities (13-items) that can be undertaken by children with epilepsy. Attitude scale had 10-items measured on 5-point Likert scale. Children with epilepsy were enrolled using consecutive sampling technique.

The inclusion criteria for enrolling sample were: children with epilepsy between 5 and 18 years and on treatment for 6 months or more, not having any other chronic illness; children and their parents who could understand/read/write Hindi and willing to participate in the study. Ethical clearance was taken from ethics committee of the institute. Informed written consent was taken from the parents and assent from the children. Confidentiality of information and anonymity of the

subjects was maintained. Subject data sheet was used to collect the demographic profile of respondents. Data were analyzed using descriptive and inferential statistics using SPSS 17.0.

RESULTS

Mean age of children with epilepsy was 9.06 ± 2.68 years. Mean age (year) at the time of onset of seizures and diagnosis was 5.9 ± 3.5 and 6.17 ± 3.5 , respectively. Majority of the children were male 42 (70%) and attending school 49 (81.67%). Most of the children 31 (51.7%) had generalized seizures followed by partial seizures 22 (36.7%). 47 (78.3%) children had frequency of seizures less than 1/month, and majority were on one antiepileptic drug 24 (40%), followed by two antiepileptic drugs 18 (30%), and remaining were on more than two drugs. Majority of the caregivers at home were mothers 53 (89.83%). Mean age of parents (father and mother) was 39.39 ± 5.8 and 33.64 ± 7 years.

For majority parents (96.7%), the primary source of information for epilepsy was medical doctor, while for few, friends 11 (18.3%); internet 9 (15%), school and TV 4 (6.7% each), folk/spiritual healer 2 (3.3%), and family 1 (1.7%) were also the primary source of information along with pediatrician/doctor. The mean knowledge and attitude scores of parents of children with epilepsy were 9.82 ± 3.9 (2-22) and 31.25 ± 9.27 (0-40), respectively.

Majority parents 50 (83.3%) had poor knowledge (<60%), few 9 (15%) had fair knowledge (60-70%) and only 1 (1.7%) had excellent knowledge ($\geq 80\%$) about epilepsy. Majority parents 33 (55%) had excellent attitude ($\geq 80\%$), while parents with good, fair, and poor attitudes were 11 (18.3%), 6 (10%),

and 10 (16.7%), respectively. Correlation between knowledge and attitude was found to be very weak and negative ($r = -0.039$, $p = 0.77$). The knowledge and attitude did not find any association with the select variables like education, occupation of parents, type of family, type of seizures, and frequency of seizures ($p > 0.05$).

The study showed that majority respondents did not have misconceptions and false beliefs related to epilepsy as shown in Table 1. Myths related to epilepsy disease were: it can be cured completely with medicines 43 (71.7%). Thirty parents (50.8%) said that a child affected with epilepsy should not wear medical identification band, epilepsy is a form of mental disorder 48 (81.4%), a child cannot have epileptic seizures when plays outside in sun 41 (69.5%), sudden change in mood of child cannot cause epilepsy 43 (71.7%), and person cannot have epileptic seizures when he/she is very angry about something 44 (73.3%).

Majority of the parents believed that activities that can be performed without caution were television viewing 28 (46.7%), walking 32 (53.3%), eating 37 (61.7%), shower bath 27 (45%), listening loud music 23 (38.3%), and household activities 40 (66.7%) (Table 2). There were some activities that could be done with caution were group games like cricket, football 29 (48.3%) and outdoor games 26 (43.3%), whereas some activities that parents believed not to be done were swimming 44 (73.3%), driving 28 (46.7%), and tub bath 30 (50%).

DISCUSSION

Present study revealed that majority of the parents 50 (83.3%) had poor knowledge about the disease per se and about the

Table 1: Misconceptions and beliefs among parents related to epilepsy (n=59)

Misconceptions and beliefs	No	Yes	Don't know
Epilepsy can be transmitted by contact	51 (86.4)	3 (5.1)	5 (8.5)
Epilepsy can be controlled with medicines	5 (8.5)	46 (77.9)	8 (13.6)
Epilepsy can be cured completely with medicines	4 (6.8)	43 (72.9)	12 (20.3)
A child with epilepsy can go to school	6 (10.2)	50 (84.7)	3 (5.1)
A child with epilepsy can perform well in studies	21 (35.5)	35 (59.4)	3 (5.1)
A child with epilepsy should not participate in any physical activities at school	41 (69.5)	12 (20.3)	6 (10.2)
Anticonvulsant medications can be stopped if there are no more seizures	51 (86.4)	3 (5.1)	5 (8.5)
A person with epilepsy should wear medical identification band	30 (50.8)	6 (10.2)	23 (39.0)
A child with epilepsy inherits it from his/her parent	47 (78.3)	6 (10)	6 (10)
Changes in the phases of the moon (e.g., full moon or new moon nights) can cause a person with epilepsy to have epileptic seizures	49 (83.1)	2 (3.4)	8 (13.5)
Epilepsy is a form of mental illness	48 (81.4)	7 (11.8)	4 (6.8)
A child can have epileptic seizures when he/she plays out in the sun for a long time	41 (69.5)	10 (16.7)	8 (13.3)
Sudden changes in weather (for example, too much heat/cold/humidity/rain) can cause a person to have epileptic seizures	46 (76.7)	12 (20)	1 (1.7)
Certain foods/drinks can make a person have epileptic seizures	51 (85)	6 (10)	2 (3.3)
A person has epileptic seizures due to sudden changes in his/her mood	43 (71.7)	10 (16.7)	4 (6.7)
A person has epileptic seizures when he/she is very angry about something	44 (73.3)	10 (16.7)	5 (6.7)

Table 2: Activities that can be undertaken by children with epilepsy (n=57)

Activities	Not to be done (f, %)	Can be done with caution (f, %)	Can be done without caution (f, %)	Do not know
Group games (e.g. cricket, football)	3 (5.3)	29 (54.7)	23 (40.5)	2 (3.5)
Outdoor games	7 (12.3)	26 (45.6)	22 (38.6)	2 (3.5)
Television viewing	4 (7.0)	19 (33.3)	28 (49.1)	6 (10.5)
Swimming	44 (77.2)	9 (15.8)	3 (5.3)	1 (1.7)
Walking	1 (1.7)	23 (40.4)	32 (56.1)	1 (1.7)
Dancing	2 (3.4)	20 (35.1)	34 (64.1)	1 (1.7)
Eating	0	20 (35.1)	37 (64.9)	0
Driving	28 (49.1)	14 (24.6)	14 (24.6)	1 (1.7)
Shower baths	4 (7.0)	23 (40.4)	27 (47.4)	2 (3.4)
Tub baths	30 (52.6)	11 (19.3)	6 (10.5)	10 (17.5)
Loud music	16 (28.1)	12 (21.1)	23 (40.4)	6 (10.5)
Going to discotheques	16 (28.1)	8 (14.0)	13 (22.8)	20 (35.1)
Household activities	1 (1.7)	15 (26.3)	40 (70.2)	1 (1.7)

triggering factors that may precipitate epilepsy 58 (96.7%) and the measures to be taken immediately 34 (56.7%). A few were completely unaware of the first aid measures 6 (10%) and many parents 10 (16.7%) expressed that they would opt for unscientific methods like placing keys in the hands of child, putting spoon in the mouth of the child, making the child smell shoe or tie the hands and legs. In occasion of epileptic attack, some parents decided to first consult faith healer 7 (11.7%) and priest 9 (15%). Self 13 (21.7%) and ayurveda 2 (3.3%) treatment were also sought for. The findings are in contrast to the findings given by Frank-Briggs and Alikor [11] in which parents were found to have good knowledge and attitude. Sakubita et al. [12] also found out that knowledge and understanding of epilepsy among parents was fairly good and attitude of parents toward epilepsy treatment was positive. They also registered low levels of contagion beliefs as in the present study.

Though the range of knowledge remains fair to poor, majority had ideas about the activities those could be performed with/without caution by their children, which is a positive fact that can lead to better practices. The attitude of parents toward children with epilepsy is influenced by the level of their knowledge about the condition. In our study, we found that parents had good attitude toward the epilepsy despite fair to poor knowledge about the disease. Majority parents 33 (55%) had an excellent attitude ($\geq 80\%$) in contrast to the findings revealed by Dung-Dung et al. [13] which was predominantly negative. The study showed less misconceptions and false beliefs related to epilepsy whereas Zaini et al. [14] reported significant misconceptions among parents. Having positive believes would have contributed to the positive attitude revealed by majority of the parents.

Small sample size, single center cross-sectional study with purposive and consecutive sampling of the children limits the generalizability of the findings. The present study may

have several implications and recommendations. Health care professionals have to play very important role in educating, parents of the affected children and the public in general, about the disease, causes, triggering factors and first aid measures to be taken at the time of onset of seizures. Periodic public lectures and informational booklet on epilepsy addressing to the issues can be used in disseminating information about the disease and its management.

CONCLUSION

In our study, majority of the parents of children with epilepsy had poor to fair knowledge scores; however, majority of them had an excellent attitude toward the disease. There is a need for developing informational booklet and conducting educational sessions on epilepsy for the parents in particular and public in general.

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