



Original Article

Determination of Parental Concerns about Seizures among Children with Epilepsy

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ABSTRACT

Epilepsy is often misunderstood and not taken seriously as compared to other diseases the reason behind it is a lack of health-related knowledge, poor economic condition, and shortness of health facilities in remote areas. **Objective:** To determine the parental concerns about seizures among children with epilepsy. **Methods:** A cross-sectional study was carried out in the Neurology division of a public hospital. After receiving informed consent, the current study involved 36 parents of epileptic patients. The parents of children with epilepsy who visited the neurology clinic (OPD) were included. The parent's concerns about seizures scale was used to measure parental worry about seizures in children with epilepsy. **Results:** 36 parents of epileptic patients were enrolled in the current study. There were 33.3% male and 66.7% female participants. The majority of the participants dealt with children having generalized seizure types. Parents were more concerned about seizures can lead to underlying disease 23(63.9), they are often concerned that their child's epilepsy has unknown cause 14(38.9), brain damage 13(36.1), loss of intelligence 17(47.2), and child developing emotional problems 13(36.1). They also show concern sometimes when a seizure may be triggered due to if they do or don't do something 22(61.1) and they also think that their child may have learning issues 11(30.6). **Conclusions:** The current study shows that parents play a vital role in improving the family functioning of epileptic families. Parents played an important role in helping children with epilepsy cope with their differences from other children.

INTRODUCTION

Epilepsy is the most serious and common neurological problem which was spread worldwide [1]. Epilepsy is an old common neurological condition. It occurs due to unprovoked spontaneous seizures [2]. Epilepsy has two or more unprovoked seizures happen more than 24 hours. Epilepsy is the chief neurological illness among children that affect approximately 50,000,000 individuals around the globe [3]. A population-based study was conducted in 1987, result of the study showed that the prevalence of active epilepsy in Pakistan was 0.98% with a 98.1% epilepsy treatment gap in the rural area. Moreover, 72.5% presence of stigma in the urban population [4]. Children having epilepsy with and other diseases face great difficulty in their social lives. Epilepsy influenced patients' family lives from different ways and creates multiple issues [5]. This

disease not only changes the patient's behavior but also disturb the life of whole family. Moreover, the parents' of the epileptic patients some time diver their perception about religious and cultural beliefs due to this disease [6]. A study was conducted on parent's perspective had shown that the combination of fever and seizure in children, develop severe anxiety in their parents as the time of despair sometimes they proclaimed that their children are dying [7]. Many parents worried during the first epileptic seizure of their children, because they have continuous complain of seizure, so that it is a reason for their worries; however, what the parents think, fortunately, this disease easily curable, and rarely causes of cerebral injuries [8]. Parents need sufficient knowledge and awareness regarding epileptic seizure that is a preventive step to lessen their

anxiety. A study conducted on 154 parents whose children were suffering from epileptic seizure; 54.3% of them were trained individuals. They had ample knowledge about the disease. It was observed that there was a direct relation between parents' knowledge and their practice [9, 10]. Parental consciousness about epilepsy is significant factor in improving their child's health. However, related issues connected to febrile fever and seizure makes more disturbances for the parents. Moreover, kids' mental health progress is parental satisfaction in life. Due to a lack of understanding, parents of epileptic patients are unable to actively participate in decision-making, role and relationship development, or effective communication [11]. They cannot manage actively epileptic seizure at home because they have no training and knowledge regarding epilepsy. Parents played an important role in helping children with epilepsy cope with their differences from other children. Due to feelings of rejection, self-blame, and humiliation, parents often avoided telling friends and relatives about their child's epilepsy, as this increased their stress levels. Therefore, this study was conducted to determine the parental concerns about seizures among children with epilepsy.

METHODS

A cross-sectional study was carried out in the Neurology division of a public hospital. After receiving informed consent, the current study involved 36 parents of epileptic patients. The parents of children with epilepsy who visited the neurology clinic (OPD) were included, while the parents of those children who had not had seizures in the previous year were excluded. The parent's concerns about seizures scale was used to measure parental worry about seizures in children with epilepsy. The Statistical Package for Social Sciences (SPSS) version 26.0 was used for the statistical analysis.

RESULTS

Table 1 showed that 36.1% were less than 35 years, whereas majority were above 35 years of age. There were 33.3% male and 66.7% female participants. The majority of the participants dealt with children having generalized seizure types.

Age (Years)	Frequency (%)
< 35 years	13 (36.1%)
> 35 years	23 (63.9%)
Gender	
Male	12 (33.3%)
Female	24 (66.7%)
Residential area	
Urban	21 (58.3%)
Rural	15 (41.7%)

Type of Epilepsy	
Generalized	24 (66.7%)
Focal	12 (33.3%)

Table 1: Demographic Characteristics of Participants (N=36)

Parents were more concerned about seizures can lead to underlying disease 23 (63.9), they often concern about that their child epilepsy has unknown cause 14 (38.9), brain damage 13 (36.1), loss of intelligence 17 (47.2) and child developing emotional problems 13 (36.1). They also show concern sometimes when seizure may be triggered due to if they do or don't do something 22 (61.1) and they also think that their child may have learning issues 11 (30.6). The overall effect of parents concern about seizure scale shows highest concern about their child (Table 2).

Sr. No.	Statements	All the Time n (%)	Often n (%)	Sometimes n (%)	Hardly Ever n (%)	Never n (%)
1	I worry that my child's seizures might be caused by an underlying problem such as a brain tumor	23 (63.9)	7 (19.4)	5 (13.9)	1 (2.8)	0 (0)
2	I worry that there might not be a known cause for my child's seizures	8 (22.2)	14 (38.9)	12 (33.3)	1 (2.8)	1 (2.8)
3	I worry that my child's seizures might be caused by something I did or did not do	3 (8.3)	7 (19.4)	22 (61.1)	3 (8.3)	1 (2.8)
4	I worry that my child might have brain damage from the seizures	9 (25.0)	13 (36.1)	10 (27.8)	3 (8.3)	1 (2.8)
5	I worry that my child might have a loss of intelligence from the seizures	11 (30.6)	17 (47.2)	3 (8.3)	5 (13.9)	0 (0)
6	I worry that my child might die from the seizures	9 (25.0)	17 (47.2)	6 (16.7)	2 (5.6)	2 (5.6)
7	I worry that my child might develop learning problems from the seizures	6 (16.7)	10 (27.8)	11 (30.6)	7 (19.4)	2 (5.6)
8	I worry about the side-effects of anti-seizure medicine on my child	6 (16.7)	9 (25.0)	16 (44.4)	2 (5.6)	3 (8.3)
9	I worry about my child developing emotional problems because of the seizures	11 (30.6)	9 (25.0)	13 (36.1)	1 (2.8)	2 (5.6)

Table 2: Parent Concerns about Seizures Scale (Pre-Intervention)

DISCUSSION

Most parents were impacted when their child was diagnosed with epilepsy because it came with a number of negative effects for the family, including "the loss of a perfect child" and the knowledge that the child might always be different from other kids due to their disease [12]. Growing up with epilepsy meant coping with a lot of uncertainty, fear, and the necessity for continuous monitoring. Parents must develop coping mechanisms for a variety of issues, including special diets, medication, academic difficulties, frequent hospital stays, behavioral issues, and more [13]. In current study 36.1% were less than 35 years, whereas majority were above 35 years of age. There were 33.3% male and 66.7% female participants. The majority of the participants dealt with children having generalized seizure types. In a study conducted in an Arab experience shows that if the caregiver was female, less educated, and parent of epilepsy patients had significant effect on their QOL. Females have to face more social, emotional and physical problems [14]. In this study majority of the participants belong to rural area. This would be the reason behind poor management and family functioning as they have not much knowledge about epilepsy, medications, nutrition, access to medical services and treatment methods. These findings were supported by different studies which showed that majority of participants were from rural area [13, 15]. According to study, people who are close to someone who has epilepsy may get uneasy around them and fear being left alone with the person's child because they are unsure of how to deal with a seizure that might occur. These are the fear of parents which lead them their concern about parents and their self-esteem get down around socialism [16]. According to studies, people who experience seizures particularly early in life and who are usually quiet and resistant to treatment are more likely to experience cognitive deficits. These deficits could also depend on other characteristics like the number, duration, nature, and antiepileptic drug therapy [17, 18]. The majority of parents

were worried about how epilepsy, if it persisted into adulthood, might affect their child's future. One of their worries was that the seizures would cause their child to experience emotional issues. According to previous research, the majority of parents of children with chronic seizures worried about their children getting married, particularly in regards to their ability to become pregnant, their ability to disclose their epilepsy before getting married, and the potential repercussions of doing so. They believed that people would react negatively to them, and this perception was influenced by how the general population treated those who had epilepsy [19, 20].

CONCLUSIONS

Parents played an important role in helping children with epilepsy cope with their differences from other child. Proper and correct support from family is essential for patient care and management.

Conflicts of Interest

The authors declare no conflict of interest.

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