

## KAP STUDY

# AWARENESS AND PRACTICES OF EPILEPTIC CARE AMONG SPECIAL EDUCATORS FOR EPILEPSY

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### ABSTRACT

**Background:** Epilepsy is a common but usually stigmatized disease due to its presentation therefore; the awareness of care givers regarding epilepsy is crucial for better management and upbringing of child. This study aims to assess the degree of apprehension among special educators, as epilepsy is more prevalent in special children.

**Method:** A cross-sectional study using questionnaire, based on interviews by 56 participants from numerous special schools of Karachi was conducted.

**Results:** All special educators knew about epilepsy through their relevant courses. 85.7% of them dealt with the epileptic person directly during their practice. They explained epileptic attack as period of seizure (71.5%), period of loss of consciousness (64.3%), and memory loss (35.7%). 57.1% perceived causes of epilepsy to be inherited, as oxygen deficiency during birth 46.4%, as birth defect 46.4%, stroke 42.9% and 39.3% believe brain tumor can be the cause. Perceived triggers were (71.4%) emotional disturbance, (67.9%) stress, (53.6%) sleep deprivation and (60%) skipping medicine. Unfortunately, 7% of them consider epilepsy as contagious disease. 11% thinks epilepsy is some kind of spiritual possession or black magic. 30% stated that epileptics should be treated by Hakims while 25% believes quacks can cure it.

**Conclusion:** Overall knowledge was adequate and attitude was positive toward epileptic children. Favorably, 70 to 80% of them supported the idea that people with epilepsy can get good education and take up a job and even can marry and have family life.

**Key words:** Epilepsy, Educators, Knowledge, Attitude, Practice

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### INTRODUCTION

Epilepsy is estimated to affect, 50 million people across the world. It is a common neurological disorder prevailing in Pakistan at a rate of 9.99 per 1000 individuals<sup>1</sup>. The prevalence of epilepsy in childhood varies from 15.5% to 23% in Pakistan<sup>2</sup>. Roughly about three fourth of the population of epileptic person is below 19 years of age<sup>1</sup>. However, it is more prevalent in children with brain disorders like cerebral palsy (as 16.4% have epilepsy)<sup>3</sup>.

Epilepsy has the predisposition to generate seizures which are inexplicable and unpredictable. It carries many misconceptions and disbelieves. It had been perceived as a sacred disease for a long time

because of its unusual clinical manifestations-sudden falls, unexpected convulsions and unpredictable course of disease<sup>4</sup>. Social stigma associated with epileptics has led to discrimination which has the more devastating effect on children than the disease itself. It has become a major issue in the education and management of epileptic children<sup>5</sup>. As a child, school-age is the major time of life for the growth of social, psychological and physical health which affects the individual's role in the society. Teachers' attitude based on their knowledge and beliefs play an immense role in the upbringing of epileptic children<sup>6</sup>. The mal-adjustment of children especially the epileptic child during school life may create a long-term impact on their personalities and psychosocial health. Therefore to minimize these

effects, factual knowledge of educator is crucial so they can manage the child during and after the seizure, since they go through a lot of psychological and emotional stress after an epileptic attack. Awareness n education must be provided to them.<sup>7</sup>

Considering the fact that children with cerebral palsy are more prone to epilepsy<sup>3</sup>, knowledge of special educators regarding the disease, its management and consequences have become really important for the social and psychological well-being of the child. Many studies done on school teachers in the different part of the world has shown lack of knowledge, misconceptions and negative attitudes towards epileptic children, which has hindered the education of epileptics in normal schools<sup>7, 8</sup>. They are rejected from schools due to their frequent convulsive episodes as it becomes challenging for both the teachers and the students<sup>8</sup>. One of the studies done in Karachi in 2014 on school teachers showed that about 27.3% thought that epileptic children are not as competent as other students. Over 28% told that epileptics have delayed growth and developmental pattern. Even, 14.5% teachers considered epilepsy as a contagious disease<sup>6</sup>. Another study done in Lower Dir showed similar results<sup>9</sup>, highlighting the fact that lack of awareness and negative attitude is still prevailing among educators which need to be addressed. School teachers are ideal to change the minds of children and parents.<sup>10</sup>Number of epileptic children is higher in Ethopia.<sup>11</sup>epileptic patients get negative impression from the society.<sup>12</sup> Communities and people should be provide knowledge regarding epilepsy.<sup>13</sup>

At present, most epileptic children are studying in special schools set up and hence the knowledge, attitude, and management practices of special educators must be sought. Until now, no study has been done to assess the awareness and practice of special educators in Pakistan. Therefore we are targeting special school teachers to evaluate their knowledge, attitude, and practices towards epilepsy. The results of study will help us to remove misconceptions and disbeliefs in educators in a long run.

The objective of the study was to determine the awareness gap for epileptic care among special educators.

## METHODS

Ethical review was obtained from the Institutional Review Board of Jinnah Sindh Medical University with the reference no. of JSMU/IRB/2016/-40. To approach our study population, approval was taken from special schools.

A cross-sectional study was conducted in special schools of Karachi to approach special educators. Almost all the institutes for special children were approached but unfortunately, only few of them allowed for interview their teachers. Institutes namely Pak Navy special school Karsaz, SCINOSA day home, ACELP, MA Aisha, Imran rehab and PNAD special school, etc. were officially approached.

The questionnaire was designed by a thorough review of literature<sup>14-21</sup> related to epilepsy and its perceptions, some amendments were made according to our society's comprehension and their values. The questionnaire was pre-tested as a pilot study on 21 participants from the general population following necessary changes in the questionnaire were made.

The questionnaire consisted of three parts, first part contained basic demographic information regarding the teacher and the school's exposure with epileptic children, number of working years of educator and time spent each day with special children. We also questioned whether they have attended any workshop or awareness seminar about epilepsy.

The second part consisted of the question in which they could use more than one option. Questions were about from where they got to know about epilepsy, how you will describe an epileptic attack, its causes and triggers and whether they have experienced any student having a seizure.

Third part consisted of Likert scale which varies from strongly agree to strongly disagree, questioning about their knowledge, attitude, and practice towards epileptic seizures. Convenience based sampling technique was used as we could not get to interview many special school teachers due to certain barriers. We collected data from 56 special educators.

Pro forma was filled questioning their knowledge, belief, perceptions and practices toward the epileptic individuals. Explained verbal consent was taken. Special educators, working in special schools having experience of at least 3 years and spends minimum 4 hours with special children were included in the study.

Data was entered and analyzed by using SPSS version 22.0.

## RESULTS

A total of 56 special school teachers were involved in the study. In all, only 3 were male educators. Out of them, 82.1% had master's degree in special

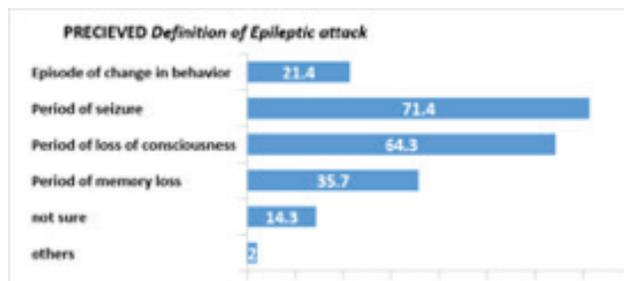
education and 17.9% were the graduates (Figure 1).



**Figure 1. Educational status of teachers of special school.**

About 60.7% of special educators have studied about epilepsy during their education, while others came to know about it through TV / Radio (14.7%), awareness seminars (7.1%) or when someone in the family was diagnosed with epilepsy (14.3%). However, 3.6 didn't know about this disease.

The majority (85.7%) of educators have seen children having a seizure during their teaching life. However upon asking them about epileptic attack almost all of them explained that presentation of epileptic attack is variable and thus chose multiple options. 71.4% explained it as period of seizure, other thought it may be a period of memory loss (35.7%) or episode of behavioral change 21.4% and 14.3 % were not sure about how it may present (Figure 2).



**Figure 2. Perception of educators about the epileptics.**

Since epilepsy has multiple causes thus, respondents gave more than one answer. 57.1% explained inheritance is the most common cause of epilepsy, head injury 53.6%, oxygen deficiency

during birth 46.4%, birth defect 46.4%, stroke 42.9%, brain tumor 39.35, infectious diseases of brain 32.1% maternal drug use 28.6%, unknown cause 10.7%, spiritual power 7.15 and 14.3 % were not aware of the cause of epilepsy (Table 1).

Most of them think that emotional disturbance (71.4%), stress (67.9%), or not taking medicine (60.7%) can trigger attack. Other triggers were sleep deprivation (53.6%), fever (35.7%), excessive hunger (25%), flashing light (25%), pregnancy/menses (17.9%) and hormonal changes (14.3%).

Fortunately, 89.3% educators did not consider epilepsy as contagious and 85.7% knew it is not a possession of spiritual power or black magic.

Most of them thought that they should not do things (like swimming 46.4% cooking 42.9%, using electrical instruments 50%, driving 42.9%) alone. About 28% strongly agreed; SA and 60.7% agreed; A with the statement that epileptics can take up jobs and about getting good education 28.6% strongly agreed and 39.3% agreed that they can. Educators were positive that epileptics can marry and have a family life 50% but they should tell their potential partners about their disease 71.4%. 39.3% strongly agreed and 35.7% agreed that they can have children.

Upon asking about treatment 39.3% SA and 17.9% A that epilepsy is a curable disease. 53.6% believe in Rohani Ilaj (dam and taweez) while 39.5% considered Hikmat as a treatment option. 67.9% SA and 32.1% A that medical treatment is effective. 52% A and 21.4% SA that epileptic drugs can cause side effects like weak memory and decreases the efficiency of the brain. 75% of educators knew that treatment should not be stopped abruptly.

Propitiously, mythical treatment to acute attack was denied. 82.1 % SD; strongly disagreed the practice of smelling shoe, socks, baam or onion, 78% SD putting a key in hand, 71.4% putting a spoon in mouth and to pour water in mouth. 46.3% considered putting a gag to prevent tongue biting, 64.3% knew that we should lay a person on his side and clear his airways.

**Table 1: Knowledge, attitude and Practice of Epilepsy.**

	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
o Epilepsy is a contagious disease	89.3%	3.6%	3.6%	3.6%
o Black magic/spiritual powers can cause epilepsy.	85.7%	3.6%	3.6%	7.1%
o Epilepsy can cause mental retardation	17.9%	21.4%	28.6%	25%
o Faith healers (quack) can treat epilepsy	53.6%	7.1%	17.9%	7.1%
o Hikmat can treat epilepsy	42.9%	7.1%	25%	3.6%
o Epilepsy is curable disease	39.3%	17.9%	25%	7.1%
o Epileptic drugs are effective in treating epilepsy	0%	0%	32.1%	67.9%

o Epileptic drugs can cause side effects like weak memory.	7.1%	3.6%	50%	21.4%
o Epileptic people can swim alone or in deep water	46.4%	25%	7.1%	10.7%
o Epileptic people can involve in cooking with fires	4.92%	7.1%	32.1%	7.1%
o Epileptic people can use power cables and other dangerous equipment	50%	25%	14.3%	7.1%
o Epileptic people can drive	42.9%	3.6%	35.7%	10.7%
o Persons with epilepsy can play games which causes physical exertion	17.9%	17.9%	32.1%	25%
o Persons with epilepsy can take up a job	3.6%	0%	60.7%	28.6%
o Child with epilepsy is able to get good education	10.7%	7.1%	39.3%	28.6%
o Persons with epilepsy remains socially out casted because of his epilepsy	35.7%	14.3%	14.3%	7.1%
o Persons with epilepsy can marry and have a family life	17.9%	0%	25%	50%
o Epileptic person should reveal it to the potential partner before marriage	7.1%	0%	21.4%	71.4%
o Epileptic patient can have children	7.1%	3.6%	35.7%	39.3%
o Epileptic drugs can be stopped abruptly if there were no seizures for 6 months.	75%	10.7%	3.6%	3.6%
o During an epileptic attack, we should make the person smell a shoe/socks/bam/onion.	82.1%	10.7%	0%	3.6%
o During an epileptic attack we should put a spoon to open his/her mouth and put some water in mouth.	71.4%	3.6%	7.1%	7.1%
o During an epileptic attack we should put a gag or cloth to prevent tongue biting.	14.3%	0%	25%	46.4%
o During an epileptic attack we should lie the person on his side and clear his air way.	0%	3.6%	32.1%	64.3%
o During an epileptic attack, we should put a key in the person's hand.	78.6%	10.7%	3.6%	0%
o During an epileptic attack, we should take the person to hospital.	17.9%	14.3%	32.1%	17.9%

## DISCUSSION

Awareness of epilepsy is crucial for the primary caregivers of the patient as their knowledge regarding nature of the disease, its presentation, and consequences, greatly affect their attitude toward the individual. Many people don't know how to respond when a person is having epileptic fits due to the misconceptions they have. This lack of knowledge may lead to the increase in the potential of inadequate or inappropriate response by the teachers or parents, not only the response and management of the condition depend on knowledge of the caregivers but their knowledge also helps them overcome the psychological or physical crisis created due to the seizures. Also, knowledge about an emergency situation such as status epilepticus is really crucial as it helps them to identify the condition so they should know when there is a need to transfer the child to hospital as in our study almost 50% said we should take them to

doctor after every attack while others were not clear about the situation.

For the purpose of better upbringing, special educators-dealing with the population more prone to epilepsy must have adequate awareness of the disease. Schools are the second home to children and their significance in personality development of a child cannot be denied. Epileptic children are enrolled in special and regular schools both but as normal school teachers are not trained for special care so we targeted special educators in our study because mostly they are taking care of the children who are more prone to fits as stated in a study that 16% of children with cerebral palsy have epilepsy.<sup>3</sup>

A study done in 2002 showed that only 35 to 40% people think they could respond to an emergency like epileptic fits. Some studies conducted in Pakistan focusing school teachers stating their knowledge, attitude, and practice of about regular

school teachers towards epileptic children<sup>6,9-12</sup>. The results were surprisingly disappointing as compared to our study done on special educators. 14.5% of teachers believe epilepsy is contagious, though the misconception is less than the general population which is 25%<sup>13</sup>. 10.9% of school teachers consider epilepsy is possession of supernatural powers. Interestingly, only 3% general population thinks so.<sup>13</sup>

Approx 41% school teachers said that they are unable to get a good education and suggested special schools for epileptic children. Probably, because 34.5% school teachers think that epilepsy can cause mental retardation and they need additional care and support. The study also reported that 4.4% teachers refused to teach such children. Per contra special educators seemed to have a more positive attitude regarding epileptic child's education (75.1%). Moreover, 37.3% school teachers said epileptic persons are socially unacceptable.

About 48.2% school teachers consider epilepsy as a curable disease and fortunately, 84.5% chose medications as a treatment option. However, 58.2% also considered faith healing methods and Hikmat (20%) as treatment options. On the other hand, 99.8% special educators selected medication as a treatment modality.

Upon asking about, what you would do during an epileptic attack, most of the teachers were misinformed. 58.2% school teachers said they would lay the child by his side and 45.5% will prevent tongue rolling. In contrast, 96.4% special educators responded that they would lay the child by his side and will prevent tongue biting (71.4%). Only 15.5% regular school teachers got their knowledge of epilepsy during their training years. However, 60.7% special educators were taught about epilepsy in their training years and they are more exposed to such cases, reflecting the reason behind their more knowledge and positive attitude towards the epileptic child.

There are almost 40 schools for special children education present in Karachi. Most of them are only for the physical disability which was excluded from our study and only those schools were targeted which specifically deal with mentally retarded children. Out of them, we could only approach a few schools due permission issues. Also, from the schools we collected data, only a few teachers were allowed for the interview. Since our sample size is too small so we can't generalize the result to the whole group but it does give a clear idea about the situation. In our study, 82% of teachers had master's degree in special education and almost 85.7% have experienced their student having a seizure but yet none of them were trained about the first aid of epilepsy and never attended any awareness session. The study shows that providing

information about epilepsy would yield a positive outcome in decreasing stigma and increasing the better outcome of first aid given.<sup>14</sup>

## CONCLUSION

Fortunately, in our study, we didn't observe the negative attitude of special educators toward patients and patient were not stigmatized to a significant extent, however regular school teachers still need to be trained about epilepsy and its management. A study<sup>12,14</sup> proposed that even single session of educating counseling was effective in improving the knowledge. This shows the necessity of a training program not only for special educator but also for all caregivers to enable them to provide a better atmosphere and adequate management to the epileptic students.

## LIMITATIONS

This study had few limitations firstly we could only visit few special schools in Karachi as many schools didn't permit, where selective teachers were offered for the interview. Most of them had their degree in special education so we missed the perception of those teachers who were not qualified in special degrees. Secondly, we worked on a very small sample of 28 educators because many schools did not grant the permission, therefore, the results cannot be generalized to whole Pakistan's educators.

## RECOMMENDATIONS

Extensive study should be conducted in different urban areas of Pakistan that will help us to organize training sessions for the educators for the betterment of epileptic children.

## ACKNOWLEDGMENT

We would like to thank Dr. Amber Tahir Siddique for her help during the initial phase of this research.

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