

## Assessment of Knowledge, Attitude and Perception about Epilepsy and the Relationship with Discrimination of Children with Epilepsy in Jos, Plateau State

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### ABSTRACT

**Introduction:** Children with epilepsy are often challenged with stigmatization and discrimination, besides the clinical effects of the disorder. This has been attributed to, among other things, poor knowledge, attitude and perception of teachers and co-learners about the disorder.

**Aim:** The study aimed to assess the knowledge, attitude, and perception of epilepsy among members of school communities in Jos and determine how it relates with discrimination of children with epilepsy.

**Methodology:** A descriptive cross-sectional study using self-administered questionnaire among 437 secondary school teachers and students in Jos, Plateau state, Nigeria. The 59-item scale comprised 36 knowledge items, 7 attitude items and 16 perception items. Chi-square and Odds ratio were used to test the hypothesis at 0.05 level of significance.

**Result:** Only about one third had good knowledge of epilepsy, (32.5% of study population). Overall, the attitude and perception of the respondents about epilepsy were good, but there were some discriminatory items exhibited. Those who had poor knowledge, attitude and perception had over three times the odds of discriminating against children with epilepsy. (OR 3.7, 95% CI=1.76-7.83). Majority, (88.3%) indicated interest in knowing more about how to respond to a child with epilepsy.

**Conclusion:** There is a need to educate members of the school about epilepsy and train them on first aid care to give a child who convulses in school. There is also need to advocate for legislation against stigmatization and discrimination of children with epilepsy.

**Keywords:** epilepsy, knowledge, attitude, perception, school members

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## INTRODUCTION

Epilepsy is one of the most common neurological problems of childhood worldwide and the most common non-infectious neurological disease in developing African countries, including Nigeria.<sup>1</sup> It has a worldwide prevalence of 5–10 per 1000 people with 80% of these people living in the developing world.<sup>2</sup> The prevalence of active epilepsy in Sub-Saharan Africa ranges from 2.2-58 per 1000 people.<sup>3,4</sup> In Nigeria, the prevalence based on defined communities, ranges from 15-37 per 1000 people;<sup>5</sup> however, it varies in the general population, being highest in the first decade of life: a critical period of social and educational development in children. After this period, the occurrence of epilepsy plateaus between the ages of 15 and 65 years, and rises again in the elderly.<sup>4,6</sup>

In many communities, children with epilepsy are often socially discriminated against on the ground of widespread negative misconceptions and beliefs.<sup>7</sup> The impact of such social discrimination contributes to the physical, psychological, and social burden of the disease, not only on individuals with epilepsy, but also on their families and the community at large.<sup>8</sup> Stigmatization and discrimination can also delay appropriate health care seeking, access to care, health financing and availability of treatment.<sup>9</sup>

The school represents a significant component of life for all children. The experiences acquired play a key role in their current and future quality of life as they spend a large amount of the critical period of their development in the school. School teachers with appropriate experiences equally play a central role in mediating epilepsy-associated stigma.<sup>10</sup> Teachers with the correct knowledge, right attitude and perception can pass same to their students and indirectly to the community, thereby minimizing discrimination of children with epilepsy.<sup>11</sup> Similarly,

co-learners can help their peers with epilepsy better integrate in the school community and the society at large. This study therefore aimed to assess the knowledge, attitude and perception of epilepsy among members of school community and determine how it relates with discrimination against children with epilepsy in Jos north local government, Plateau state, Nigeria.

## METHODOLOGY

This was a cross-sectional descriptive study involving teachers and students from the senior secondary school sections of selected secondary schools in Jos north Local Government Area (LGA). The Jos north LGA is one of the seventeen LGAs in Plateau State, Nigeria. The Local Government Area is bounded in the east by Jos East Local Government Area; to the south by Jos South Local Government Area; to the west by Bassa Local Government Area and to the north by Bauchi State.<sup>12</sup> Out of a total of 94 secondary schools in the LGA, 68 are private-owned and 26 are government schools.

Multistage sampling technique was used. By proportionate sampling, 3 schools (2 private and one public school) were selected from a ward. In the schools, eligible teachers and students were selected by systematic sampling using the class register for the students. Teachers were sampled using simple random sampling.

Teachers and students in the senior secondary school section of the eligible schools who consented were included in the study. Teachers and students who had been diagnosed with epilepsy or who are currently on treatment for seizure disorder and those who declined participation were excluded from the study. Ethical approval was obtained from the Health and

Research Ethics Committee of the Bingham University Teaching Hospital, Jos. Approval for study was also obtained from the school heads. Written consent was obtained from the students and the teachers. For students not up to the age of giving consent, assent was obtained from them while consent was obtained from their parents/guardian/school teacher.

All the provisions of the Helsinki declaration were duly observed.

The survey instrument was a pre-tested self-administered questionnaire in English language, designed to evaluate knowledge, attitudes and perception with respect to epilepsy. The questionnaire was investigator designed, following literature search of other questionnaires from similar studies. The questionnaire was in two parts; the first section elicited demographic information including age, sex, school category, educational level (class for students and educational qualification with respect to teachers); while the second part elicited awareness and knowledge of epilepsy (knowledge of cause, manifestation of epilepsy, treatment of epilepsy and source of information), attitude toward epilepsy and perception about epilepsy. The item scale for this scale was developed through a review of literature, including previously published studies of knowledge, attitude, and perception of epilepsy. The 59-item scale included 36 knowledge items, 7 attitude items and 16 perception items. Respondents were asked to answer 'yes' or 'no' on some items and to rate some statements as 'agree', 'disagree' or 'undecided'.

### Data Analysis

Data collected was analyzed using IBM SPSS (Statistical Package for Social Science) software (version 25.0). Continuous variables such as age were expressed as the range and median, whereas categorical variables were presented as frequencies

(%). Chi-square test was used to examine the association between responses and each demographic variable in a bivariate analysis. Significance level was set at  $P < 0.05$ . Results are presented in tables and figures as appropriate.

## RESULTS

There was a total of 437 participants, 60 teachers and 377 students. Table 1 shows the sociodemographic characteristics of the study population.

**Table 1: Sociodemographic characteristics of study population**

Characteristics	Teacher (N=60)		Student (N=377)	
	Frequency	Percentage	Frequency	Percentage
<b>Sex</b>				
Male	24	40.0	180	47.8
Female	36	60.0	189	50.1
Unanswered	0	0.0	8	2.1
<b>Highest level of education</b>				
JSCE	0	0.0	368	97.6
SSCE	1	1.7	0	0.0
NCE	12	20.0	0	0.0
First degree	39	65.0	0	0.0
Masters degree	8	13.3	0	0.0
Unanswered	0	0.0	9	2.4

Overall knowledge, attitude and perception

Table 2 shows that only 32.5% of the respondents had good knowledge of epilepsy and majority (55.4%) had a fair knowledge of epilepsy. Majority, 337 (77.1%), of the respondents had positive attitude towards children with epilepsy while 57.9% had poor perception of epilepsy

**Table 2: Overall knowledge, attitude, and perception of study population about epilepsy**

Parameter	Frequency	Percentage (%)
<b>Level of knowledge</b>		
Poor	53	12.1
Fair	242	55.4
Good	142	32.5
<b>Attitude</b>		
Negative	97	22.2
Positive	337	77.1
Unanswered	3	0.7
<b>Perception</b>		
Poor	253	57.9
Good	177	40.5
Unanswered	7	1.6

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**Table 3: Selected item responses showing awareness and knowledge of epilepsy**

Selected Items	Respondent that indicated 'yes' with item			
	Teacher (N=60)		Student (N=377)	
	Frequency, n	Percentage	Frequency, n	Percentage
<b>Awareness</b>				
Ever heard about epilepsy	57	95.0	333	88.3
Knows someone with epilepsy	35	58.3	147	39.0
<b>What is epilepsy?</b>				
Spiritual disorder	3	5.0	18	4.8
Psychiatric disorder	5	8.3	81	21.5
A disorder from birth trauma or brain tumour	31	51.7	199	52.8
An infectious disease	6	10.0	17	4.5
I do not know	12	20.0	46	12.2
<b>Manifestation of epilepsy</b>				
Jerking body	29	48.3	153	40.6
Loss of consciousness	30	50.0	90	23.9
Staring temporarily	6	10.0	28	7.4
Foaming from the mouth	37	61.7	236	62.6
I do not know	6	10.0	31	8.2
<b>Who should treat epilepsy?</b>				
Doctor	54	90	300	79.6
Pastor/Imam	5	8.3	41	10.9
Herbalist	8	13.3	13	3.5
I do not know	2	3.3	12	3.2
<b>When someone is convulsing, you should:</b>				
Move away	6	10.0	19	5.0
Put something in the mouth	32	53.3	192	50.9
Call a doctor	22	36.7	188	49.9
Start praying	11	18.3	54	14.3
Do nothing	1	1.7	10	2.7
Give cow's urine	2	3.3	7	1.9
Reassure and help him/her stand up after convulsing	17	28.3	98	26.0

**Knowledge**

Table 3 shows the list of individual knowledge items. Only 5% of the teachers and 11.7% of the students had never heard of epilepsy. About half of the respondents

(51.7% of teachers and 52.8% of students) knew that epilepsy is a disorder that results from brain tumour and birth trauma. There were 3 (5%) teachers and 18 (4.8%) students who considered it a spiritual

problem while 12 (20%) teachers and 46 (12.2%) students did not know the cause of epilepsy.

Majority of the teachers, 37 (61.7%) and students, 236 (62.6%) indicated that epilepsy manifests with foaming in the mouth. Only 6 (10%) and 28 (28%) of teachers and students respectively know that epilepsy can manifest by staring.

The table also shows that most of the respondents (90% teachers and 79.6% students) indicated that doctors should be the ones to treat epilepsy. While 13% of teachers and 3.5% of students indicated that treatment should be by herbalist.

There were 53.3% teachers and 50.9% students who would put something in the mouth of the person convulsing. Far less than half of the teachers, 22 (36.7%) would call a doctor when someone nearby is convulsing and only 17 (28.3%) of them would reassure and help the person up after a convulsion. There were 2 (3.3%) teachers who indicated that they would give cow urine to the person convulsing. Five percent of the students indicated that they would move away from the person while 10 (2.7%) students would do nothing.

### Attitude

Table 4 shows that a breakdown of the various items that showed the attitude of the teachers and students towards children with epilepsy. There were 19 (31.7%) teachers and 164 (43.5%) students who indicated that they were afraid of epilepsy but less than half of the teachers (38.3%) and students (48.5%) would keep a friend with epilepsy. Majority of the teachers, 50 (83.3%) and 307 (81.4%) students indicated that they would share their books with children with epilepsy but only 48.3% and 37.1% respectively would eat with a person with epilepsy. A third of the teachers, 20 (33.3%) and about a quarter of the students, 94 (24.9%) would allow their relative to marry a person with epilepsy. Only 3.3% of the

teachers and 17.2% of the students stated that they had training to handle any form of convulsion. A large proportion, 86.7% of the teachers and 83.3% of the students are willing to have more information about how to respond if a student has epilepsy.

### Perception

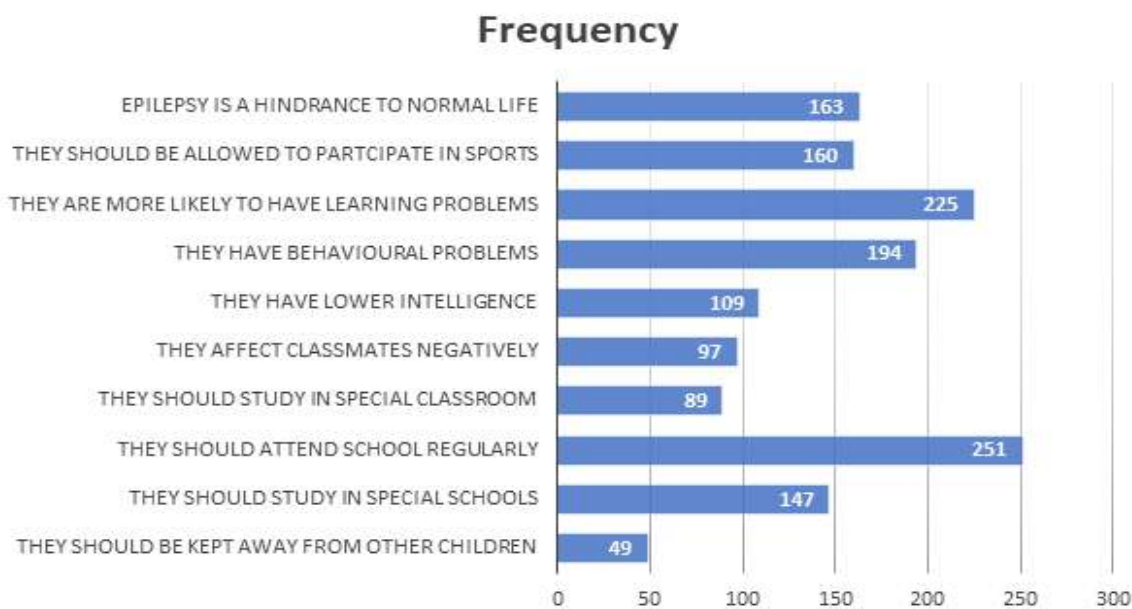
Figure 1 shows that 147 (33.6%) respondents who indicated that children with epilepsy should study in special schools. Eighty-nine (20.4%) of the respondents indicated that they should attend regular schools with other children but be placed in special class. About half, 225 (51.5%), of them indicated that children with epilepsy are more likely to have learning problems compared to those without epilepsy. There were 49 (11.2%) respondents who indicated that children with epilepsy should be kept away from other children and 97 (22.2%) who felt they would negatively affect non-epileptic classmates.

Relationship between knowledge, attitude, and perception of epilepsy and discrimination

Table 5 shows that there is a relationship between having poor knowledge, attitude, perception of epilepsy and discrimination of children with epilepsy. The analysis also shows that those who had poor knowledge, attitude and perception of epilepsy were 3.7 times more likely to discriminate against children with epilepsy.

**Table 4: Selected items responses showing attitude towards children with epilepsy**

Selected Items	Respondents that agree with item			
	Teacher (N=60)		Student (N=377)	
	Frequency, <b>n</b>	Percentage	Frequency, <b>n</b>	Percentage
I would like to keep a friend with epilepsy	23	38.3	183	48.5
I would play with a friend with epilepsy	37	61.7	222	58.9
I am ready to handle any form of epilepsy if it happens in my class	34	56.7	189	50.1
I would eat with someone with epilepsy	29	48.3	141	37.1
I can share my books with someone with epilepsy	50	83.3	307	81.4
I am afraid of epilepsy	19	31.7	164	43.5
People with epilepsy can marry my relative	20	33.3	94	24.9
I have sufficient training in handling any form of seizure	2	3.3	65	17.2
I would like to have more information about how to respond if a student has epilepsy	52	86.7	316	83.8



**Figure : Perception of respondents about children with epilepsy**

**Table 5: Chi-square ( $\chi^2$ ) and Odds ratio (OR) showing relationship between knowledge, attitude and perception and discrimination**

Level	Discriminates	Not Discriminates	DF	$\chi^2$	OR (95%CI)	p-value
Poor KAP	29	48	1	12.702	3.7 (1.76,7.83)	.0004
Good KAP	13	80				

*p-value: significant at 0.05 level, DF=1, CI-confidence interval*

## DISCUSSION

The findings in this study showed that the members of school communities (teachers and students) in Jos North local government had high level of awareness but majority had poor to fair knowledge of epilepsy. Their overall attitude and perception towards children with epilepsy was impressive. Previous studies have also observed similarly low level of knowledge about epilepsy.<sup>13-17</sup> As indicated in previous studies, many of the teachers have inadequate knowledge in their training as teachers. Suffice to say that if the teachers do not have enough training in knowledge of epilepsy, it will be difficult to pass adequate knowledge to the students that they teach.

Some members of the school community think that epilepsy is a spiritual problem while some others think it is a psychiatric problem. Although the number of those with such knowledge was lower than that obtained in Kano,<sup>14</sup> it reflects the level of knowledge of the teachers and students who are expected to be educated members of the society. This may also reflect the level of knowledge of the general populace which the school members also belong to. This belief that epilepsy is a spiritual or psychiatric problem is also prevalent in other parts of the country and other developing countries of the world.<sup>13,18,19,20</sup>

The study revealed that most of the respondents were not familiar with the different manifestations of epilepsy. As observed in this study, majority only

recognized jerky movement and foaming from the mouth as manifestation of seizure, and just a handful of the teachers and students knew that epilepsy could manifest as staring temporarily (absence seizure). These findings have implications for in-school recognition of a seizure as those with absence seizure or those not foaming in the mouth will go unnoticed. For example, a teacher who is unaware of the symptoms of absence seizures may incorrectly characterize a child as inattentive or forgetful when the child is, in fact, missing instructional material during seizures. However, discerning an absence seizure or a sensory seizure without prior training can be a difficult task in the absence of twitching, foaming, and loss of consciousness. Teachers should therefore be provided with educational materials and in-service training that covers a child's specific seizure symptoms whenever a child with epilepsy is a member of their class. This will also correct misconceptions about epilepsy which have been attributed to a lack of organized information campaigns and low levels of preparedness for teaching students with epilepsy.<sup>21,22,23</sup>

The procedure of putting object in the mouth of a person convulsing raises concerns as to the potential harm the individual may suffer due to this erroneous practice. Though this study did not directly ask the

members of the school community details about trainings they had on epilepsy, it can be inferred from the high percentage of respondents who indicated interest to have more knowledge. The import of this finding is significant as potentially harmful measures may be undertaken during a seizure attack such as inserting hard objects into patients' mouth or pulling their tongues or giving cow's urine as indicated by some respondents. The knowledge about what to do when a child has a seizure is of utmost importance, as the consequences of not knowing what to do, or doing the wrong thing, could be harmful to the child having the seizure. From the responses of the study group, it is clear that there is need for a training on first aid care to be given to a convulsing person.

The overall attitude of both teachers and students in the schools studied was quite impressive. Other researchers have shown that over the last 50 years, the general attitude and perception towards people with epilepsy have gradually improved.<sup>13</sup> However, individual item analysis revealed some troubling trend as some members of the school communities expressed fear of epilepsy. It has been recognized that the fear of epilepsy often leads discrimination and stigmatization which in turn affects the learner's everyday activity.<sup>11</sup> If a teacher reacts with fear or any other negative attitude towards children with epilepsy, he will instill the same negative attitude among the other students.<sup>24</sup>

While there was generally good perception of epilepsy, the composite perception individually revealed some prejudiced responses against children with epilepsy. While majority of the respondents agreed that children with epilepsy should attend school regularly, many perceived they should be in special schools or in a special class separate from other students. This finding is similar to finding by Owolabi who observed that 25% of school teachers objected to having a child with epilepsy in their class.<sup>14</sup> Another

observation made in the study is the decline of the respondents to allow their family members to marry someone with epilepsy. Ekenze and Ndukuba<sup>25</sup> reported a similarly high refusal rate in eastern Nigeria. Other studies have reported similarly high prevalence of refusal, with varying prevalence ranging from 55% in Kuwait, 57% in Russia, 66% in Greece, 82.5% in Ethiopia and 94% in Republic of Korea.<sup>26,27,28</sup> The finding in this study and previous studies lend support to report by Singh et al,<sup>29</sup> that people with epilepsy frequently experience problems in marriage, including reduced marital prospects, poor marital outcomes and diminished quality of married life. This reduction in marriage prospect reflects high tendency towards stigmatization and discrimination as has been observed in this study and other studies.<sup>30</sup> Other discriminatory tendencies observed in this study may be experienced by not just the students but also their family members. Although this study did not seek to establish discrimination against family members or care givers of children with epilepsy, other researchers have observed that discriminatory behaviours are extended to the parents of children with epilepsy.<sup>31,32</sup>

The finding that those who had poor knowledge, attitude and perception of epilepsy were three times more likely to discriminate against children with epilepsy supports is in tandem with previous studies<sup>33,34</sup> that have shown that inaccurate, inadequate, or even erroneous knowledge leads to poor perception and approach to epilepsy. Ekeh and Ekrikpo<sup>34</sup> found that even in the higher institution, clinical medical students, as opposed non-clinical medical students, were more informed about epilepsy and had better attitude and perception towards epilepsy and were less likely to discriminate against persons with epilepsy.<sup>34</sup>

Unfortunately, besides low self-esteem that arises



from social discrimination, other negative consequences are educational under-achievement and learning disabilities, poor performance in class and loss of learning opportunity.<sup>35,36</sup> Additionally, such negative social behaviour negatively affect the quality of life and have consequence on social inclusion.

Improving knowledge and raising awareness of epilepsy in schools, work places, and communities is needed to reduce stigma. This study has revealed the poor knowledge of teachers and students and some pervasive attitude and perception about epilepsy. This deficit, as observed in this study and previous studies<sup>37</sup> brings to fore the gap that there is no formal training in handling learners with epilepsy. Yet a majority of teachers and students indicate interest in acquiring such knowledge and skill.

To reduce stigma and discrimination, funds need to be directed toward epilepsy awareness and stigma-reduction programmes. A multisectoral public health response needs to include interventions that improve the knowledge of individuals and their families, teachers, employers, health care providers, disability service providers, care providers, first responders, traditional healers, media, community, and policymakers. In addition, legislation based on internationally accepted human rights standards can prevent discrimination and rights violations, improve access to health care services, and raise the quality of life for people with epilepsy.

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