

## Original Research Article

# The impact of an enlightenment program on community perception towards children with epilepsy

Eyong Komomo Ibor\*, Ekanem E. Emmanuel, Asindi A. Asindi,  
Chimaeze Torty, Brown-Abang E.

Department of Paediatrics, University of Calabar, Nigeria

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### \*Correspondence:

Dr. Eyong Komomo Ibor,

E-mail: [komomoeyong@yahoo.com](mailto:komomoeyong@yahoo.com)

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### ABSTRACT

**Background:** Epilepsy is associated with social stigma and discrimination which is often harmful and devastating. Lack of knowledge and misconception is responsible for these negative attitudes. Public awareness and education are known to improve perception towards epileptics.

**Methods:** A sensitization workshop among community leaders on epilepsy was carried out in a rural community in Cross River State, Nigeria. A pretest questionnaire was administered to participants based on items related to knowledge and perception towards epileptics. The respondents were offered a 2-hour workshop on the causes, types, cure and myths about epilepsy. The same questionnaire was again applied after the workshop. The responses before and after intervention were compared using the McNemar test statistic, with a significance level at  $p < 0.05$ .

**Results:** Seventy-two respondents participated in the study comprising of 42 (58.3%) males and 30 (41.7%) females. Twenty-eight (38.9%) had primary education and the same number had tertiary education. There was a positive correlation between level of education and performances in the perception towards various domains of epilepsy. Statistical significant differences were found in perceptions regarding cure, mode of contracting epilepsy and potentials of epileptics. However, no statistical difference in perception after the intervention regarding marriage to epileptics.

**Conclusions:** Respondents with higher level of education demonstrated significantly better awareness and attitude towards epileptics compared to those with lower levels the intervention package produced a significant improvement in most domains of perception about epilepsy. Public enlightenment is effective in reducing social stigma and discrimination. It should be encouraged to curtail the negative attitude and perception towards epileptics.

**Keywords:** Enlightenment, Epilepsy, Perception

### INTRODUCTION

Epilepsy is a condition of chronic, recurring seizures and its most disabling aspect is unpredictability of when and where the next seizure will occur.<sup>1</sup> This disease carries a great social stigma, and the resulting discrimination is often more harmful and devastating than the disease itself.<sup>1</sup>

Although the causes of stigma are complex, a lack of knowledge about epilepsy has been considered to be an important factor in the negative attitudes towards people with this clinical condition. Epileptics are sometimes victims of discriminatory attitudes, and unnecessary, if not dangerous measures are applied in an attempt to assist them during an epileptic fit.<sup>2,3</sup>

Social discrimination against people with epilepsy is largely due to misconception about the disease, and the horror that strikes members of the public when confronted by the frightening sight of a person suffering from epilepsy.<sup>4</sup> Previous studies have shown improved public attitude and a greater understanding of epilepsy in developed countries due to increasing public awareness and education. This does not seem to be the case with developing countries where public attitude towards epileptics is still poor and epileptics are still widely stigmatized.<sup>4-7</sup>

An earlier study on stigma on Nigerian children living with epilepsy showed that children claimed being made object of ridicule, with forty percent considered as demon possessed and others as being mad or cursed.<sup>8</sup> A variety of inappropriate and even harmful seizure control measures are often adopted, the infliction of burns, rubbing irritant to the eyes, holding patients over fire, administration of cow urine.<sup>4-6</sup> The education of the population is thus important in order to revert this discriminatory and stigmatizing situation by the multiplying effect of knowledge and positive attitudes.<sup>9</sup>

The aim of this study was to evaluate the results/outcome of an enlightenment campaign on epilepsy on the knowledge and perception of rural dwellers in Ibogo, Biase local government area of cross river state, Nigeria.

## METHODS

The study was carried during a sensitization workshop on epilepsy in February 2017 in a rural community Ibogo, in Biase in Local Government Area of Cross River State, Nigeria among community leaders; including age group heads, leaders of socio cultural groups, religious leaders and leaders of thoughts in the community. The study was carried out using questionnaire based on items related to familiarity, knowledge, attitudes and care of patients during an epileptic fit and consisting of questions already applied in other surveys.<sup>3,9,10</sup>

A pretest questionnaire was administered, and measures were taken to ensure that the respondents answered the questions independently. The respondents were then offered a workshop lasting for about two hours, consisting of the presentation of audio-visual material about epilepsy, followed by a brief discussion on the causes of seizures, types of seizures, causes, treatment and myths about epilepsy. The questionnaire was then applied again (2<sup>nd</sup> phase of the survey). All the respondents in the first phase completed the questions in the second phase

### Data analysis

The responses before and after intervention (1<sup>st</sup> and 2<sup>nd</sup> phases, respectively) were compared using the McNemar test statistic, with a significance level set at  $p < 0.05$ .

## RESULTS

Seventy-two respondents participated in the study, out of which 42 (58.3%) were males while 30 (41.7%) were females. The male: female ratio was 1.4:1. The largest number of participants was from the age group 20 to 30 years representing 43.1% of the respondents while the least represented age group was those aged <20 years representing (5.6%) of the respondents (Table 1). Majority of the respondents (87.5%) were Christians. Twenty-eight (38.9%) had primary education and the same number of participants also had tertiary education, while 16 (22.2%) had secondary education. Sixty-nine (95.8 %) of the 72 respondents have either heard, knows about or seen someone with epilepsy before the study.

**Table 1: Socio-demographic characteristics of study participants (N=72).**

Variable	Frequency	Percentage (%)
<b>Sex</b>		
Male	42	58.3
Female	30	41.7
<b>Age group/years</b>		
<20	4	5.6
20-30	31	43.1
31-40	19	26.4
41-50	18	25.0
<b>Religion</b>		
Christianity	63	87.5
Islam	9	12.5
<b>Educational qualification</b>		
Primary	28	38.9
Secondary	16	22.2
Tertiary	28	38.9

Table 2 shows association between respondents' highest level of education and their perception towards epilepsy. A greater proportion of those who said it can be treated had tertiary education and the difference was statistically significant ( $p=0.005$ ). Among those who said it cannot be cured, a significantly higher proportion had only primary education ( $p<0.001$ ). Similarly, greater proportions of respondents who perceived that epilepsy can be contacted by touch (71.4%), touching saliva (99.9%), living in same house (87.5%) attained either primary (mostly) or secondary education. The difference was statistically significant ( $p<0.05$ ). A higher proportion of those who perceived epileptics had a bright future (82.1%) attained tertiary education and the difference was also statistically significant ( $p<0.001$ ).

Table 3 shows respondents' perception towards epilepsy before and after the educational intervention. A statistically significant difference was found in their perceptions regarding whether epilepsy can be cured ( $p<0.001$ ), contacted by body contact ( $p<0.001$ ), contacted by touching saliva ( $p<0.001$ ), contracted by living in the same house ( $p<0.001$ ) and, whether they

have a bright future ( $p < 0.001$ ). However, there was no difference in perception before and after the intervention regarding whether it can be treated ( $p = 0.210$ ) and

whether they will allow their children marry epileptic ( $p = 0.062$ ).

**Table 2: Association between level of education and perception towards epilepsy.**

Variable	Level of education			Total (n=72)	P-value
	Primary (n=28)	Secondary (n=16)	Tertiary (n=28)		
<b>Can it be treated?</b>					
Yes	16 (57.1)	11 (68.8)	26 (92.9)	53 (73.6)	FET (0.005*)
No	12 (42.9)	5 (31.2)	2 (7.1)	19 (26.4)	
<b>Can it be cured?</b>					
Yes	2 (7.1)	2 (12.5)	20 (71.4)	24 (33.3)	Chi square (<0.001*)
No	26 (92.9)	14 (87.5)	8 (28.6)	48 (66.7)	
<b>Contracted by body contact?</b>					
Yes	20 (71.4)	11 (68.8)	10 (56.9)	41 (56.9)	Chi square (0.015*)
No	8 (28.6)	5 (31.3)	18 (64.3)	31 (43.1)	
<b>Contacted by touching saliva?</b>					
Yes	26 (92.9)	16 (100.0)	8 (28.6)	50 (69.4)	FET (<0.001*)
No	2 (7.1)	0 (0.0)	20 (71.4)	22 (30.6)	
<b>Contacted by living in same house?</b>					
Yes	5 (17.9)	2 (12.5)	17 (60.7)	24 (33.3)	Chi square (<0.001*)
No	23 (82.1)	14 (87.5)	11 (39.3)	48 (66.7)	
<b>They have bright future?</b>					
Yes	9 (32.1)	4 (25.0)	23 (82.1)	36 (50.0)	Chi square (<0.001*)
No	19 (67.9)	12 (75.0)	5 (17.9)	36 (50.0)	

\*=Statistically significant

**Table 3: Comparison between perception towards epilepsy before and after educational intervention (N=72).**

Response before intervention	Response after intervention		McNemar test statistics	P-value
	Yes	No		
<b>Can it be treated?</b>				
Yes	45 (62.5)	8 (11.1)	-	0.210
No	15 (20.8)	4 (5.6)		
<b>Can it be cured?</b>				
Yes	23 (31.9)	1 (1.4)	38.205	<0.001*
No	43 (59.7)	5 (6.9)		
<b>Contacted by body touch?</b>				
Yes	0 (0.0)	41 (56.9)	39.024	<0.001*
No	0 (0.0)	31 (43.1)		
<b>Contacted by touching saliva?</b>				
Yes	0 (0.0)	50 (69.4)	48.020	<0.001*
No	0 (0.0)	22 (30.6)		
<b>They have a bright future?</b>				
Yes	35 (48.6)	1 (1.4)	29.257	<0.001*
No	34 (47.2)	2 (2.8)		
<b>Contacted by living in same house?</b>				
Yes	24 (33.3)	0 (0.0)	46.021	<0.001*
No	48 (66.7)	0 (0.0)		
<b>Allow your child marry epileptic?</b>				
Yes	67 (93.1)	0 (0.0)	-	0.063
No	5 (6.9)	0 (0.0)		

(Test statistics=McNemar Test), \*=statistically significant

## DISCUSSION

The study revealed that the majority of respondents were aware of epilepsy. This is similar to the findings of Njamnshi et al in Cameroun and kabir et al in Northern Nigeria who demonstrated high level of awareness of epilepsy among rural dwellers.<sup>10,11</sup> This however contrast the findings in the rural communities in Uganda and some sub-Saharan Africa countries where despite the fact that epilepsy is one of the most common neurological disorders, the knowledge about epilepsy was generally poor.<sup>12,13</sup>

Respondents with higher level of education demonstrated significantly better awareness and attitude towards epileptics compared to those with lower level of education prior to the enlightenment program. These findings collaborated with studies in Malaysia, which showed that a higher level of education correlated positively with awareness, knowledge and attitudes concerning epilepsy.<sup>14,15</sup> Similarly, community-based studies have also reported that better-educated individuals offer more favourable opinions and display more positive attitudes towards people with epilepsy.<sup>16,17</sup>

Previous studies have shown the impact of intervention course on the various domains of epilepsy. It has been found that shorter and less complex intervention programs have beneficial results in providing enlightenment about knowledge, attitude, and perception regarding epilepsy and care during epileptic seizures.<sup>17,18</sup> Similar findings were seen in our study. After the intervention package, there was a significant improvement in almost all the domains of perception about epilepsy.

A significant number of the respondents who hitherto did not think that epilepsy can be cured now believed that people with the disease can be cured and that people living with epilepsy can be completely free from the disease with appropriate treatment with orthodox medications. Similarly, there was a positive change in the perception about living in the same house with epileptics as a significant number of the respondents would now live in the same house with epileptics, since they now know that the disease is not contracted by touching or having contact with epileptics. This change in perception will significantly reduce the problem of stigmatization of children and people living with epilepsy.

The enlightenment program also impacted positively on the perception of the respondents in the area of how the disease can be contracted. It is an age long belief in some communities in Africa that epilepsy is contagious and that the disease can be contracted by having physical contact with an epileptic or touching the saliva of an epileptic.<sup>19-21</sup> These perceptions were changed following the enlightenment program. The implication of the positive change in perception in these domains considered is that stigma on epileptics would be curtailed

and epileptic would receive help during attacks. Also, there was a positive change in perception of the respondents that children with epilepsy do not have a bright future as a significant number of the participant now believe that epileptics have the ability to achieve their full potentials. The enlightenment program did not significantly affect the respondent's perception towards allowing their children to marry epileptics. This perception is in tandem with the lack of support and resistance to marriages of epileptic amongst respondents in a study among Igbos in Eastern Nigeria who will want to preserve the 'purity' and 'integrity' of the family.<sup>22</sup> Similarly, in some cultures in China, a survey on public awareness on epilepsy in 1992 showed that 72% of the respondents objected to their children marrying someone with epilepsy.<sup>23</sup> In both China and India epilepsy is commonly viewed as a reason for prohibiting or annulling marriages.

## CONCLUSION

lack of knowledge and misconception about epilepsy are important factors in the negative attitude and discrimination towards epileptics. A short but focused enlightenment program in the study has proved to have positive impact on the various domains of epilepsy leading to change in perception. Concerted efforts should be made towards public education as this would significantly reduce the social stigma, discrimination and negative attitude children living with epilepsy.

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