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Epilepsy prevalence, potential causes and social beliefs in Ebonyi State and Benue State, Nigeria

Chijioke Osakwe[a,*], Willem M. Otte[b,c,d,1], Chimhurumnanya Alo[e]

[a] World Health Organization, Enugu, Nigeria
[b] Community-based Rehabilitation Effata, Waddinxveen, The Netherlands
[c] Department of Pediatric Neurology, Rudolf Magnus Institute of Neuroscience, University Medical Center Utrecht, The Netherlands
[d] Biomedical MR Imaging and Spectroscopy Group, Image Sciences Institute, University Medical Center Utrecht, The Netherlands
[e] Department of Community Medicine, Federal Teaching Hospital, Abakaliki, Ebonyi State, Nigeria

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Summary Epilepsy is a common neurological disorder in Nigeria. Many individuals are affected in rural areas, although prevalence data is not available. In this study we aimed to establish the prevalence of epilepsy in a rural community in south-east Nigeria, a community suspected for having a high number of people living with epilepsy. We compared this with the prevalence in a nearby semi-urban community in north-central Nigeria. In both communities we identified potential causes of epilepsy and obtained information on the social beliefs regarding epilepsy. We used door-to-door surveys and focus group discussions.

The epilepsy prevalence in the rural community was 20.8/1000 [95% confidence interval (CI): 15.7—27.4]. The prevalence in the semi-rural community was lower, namely 4.7/1000 [CI: 3.2—6.9]. The difference in prevalence was highly significant (χ^2-test, $p < 0.0001$). In both communities most people with epilepsy were in the age range of 7—24 years. Causes that might be contributory to the prevalence of epilepsy in both communities included poor obstetric practices, frequent febrile convulsions, head trauma, meningitis and neurocysticercosis. In both communities we found stigma of people with epilepsy.

* Corresponding author.
E-mail addresses: chijiosakwe@yahoo.com (C. Osakwe), wmotte@gmail.com, wim@invivonmr.uu.nl (W.M. Otte).
[1] Address: Pediatric Neurology, UMC Utrecht, Yalelaan 2, 3584 CM Utrecht, The Netherlands. Tel.: +31 30 253 5568; fax: +31 30 253 5561.

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In conclusion, the epilepsy prevalence in the semi-urban community is similar to that in industrialized countries. In contrast, the rural community has a much higher prevalence. This may require the establishment of specific community-based epilepsy control programs. Community interventions should focus on treatment of acute epilepsy and on stigma reduction.

Introduction

Epilepsy is a common and chronic neurological disorder which affects 60 million people worldwide (Ngugi et al., 2010; Thurman et al., 2011). Most people with epilepsy (PWE) live in low- and middle-income countries. However, for many sub-Saharan countries the exact prevalence remains unknown (Prilipko, 2005; Ngugi et al., 2010).

Nigeria is the most populous country in Africa and accounts for about 18% of the continent's total population. Nevertheless, the latest epilepsy prevalence data for Nigeria were published 25 years ago and were obtained from a single town in south-west Nigeria (Osuntokun et al., 1987). There is obviously an urgent need to get more and updated prevalence data. In particular from rural areas where epilepsy is suspected to be more prevalent as compared to urban regions, due to parasitic infection. As a result of poor sanitation and free-range pig management, neurocysticercosis is a common cause of epilepsy in pig breeding areas (Nsengiyumva et al., 2003; Phiri et al., 2003). Onchocerciasis, a common parasitic infection in south-east Nigeria, is also associated with the cause of epilepsy (Pion et al., 2009).

Based on anecdotal data from two community-based epilepsy control programs in Ebonyi State in south-east Nigeria, it is thought that epilepsy is highly prevalent in the rural local government area Izzi. In particular the Ochiohu community stands out in the number of PWE known to the community workers.

In this study we estimated the prevalence of epilepsy in this rural Ochiohu community and compared it to the epilepsy prevalence obtained from a close by semi-urban community. The information was obtained through semi-structured interviews in all households in both communities.

To anticipate on future interventions, we also identified potential causes for epilepsy and the acceptance of, and attitudes toward PWE using focus group discussions. The results obtained from this study may specifically be used to guide community-based treatment services and educational and social interventions that try to reduce the burden of epilepsy in rural south-east Nigeria.

Methods

Our study consisted of a descriptive approach employing quantitative semi-structured face-to-face interviews and qualitative focus group discussions in a rural and semi-urban community in Ebonyi state and Benue state respectively, in Nigeria.

Ethics

The study protocol was approved by the state ministry health ethics committees in both locations. The study aim was clearly explained to all participants in the interviews and focus group discussions. Anonymity was obtained through the assignment of numbers rather than location of households, or names of respondents, during data collection.

Study location

The geographical location of the two communities is shown in Fig. 1. Population sizes were obtained from local government officials. In Ebonyi state we included the Ochiohu community, located in Izzi Local Government Area (LGA). This rural community is among the poorest communities in Ebonyi State and has a population of 2500 persons. There is one primary school. Public or private health facilities are not available.

In Benue state we included the Ogobia community, located in Otukpo LGA. Ogobia is characterized as semi-urban and has a population of 6000. It contains five primary schools, six secondary schools, one mission hospital and two private hospitals.

A sample size calculation was done before the study was conducted to know the precision of the estimations. This was based on data that showed that epilepsy was two or three times more common as compared to industrialized countries (5—10 per 1000 people; (Preux and Druet-Cabanac, 2005)). A population size of 2500 with a prevalence of 5 per 1000 people leaded to an estimation precision of 0.10% (http://sampsize.sourceforge.net/).

Questionnaires

All households in the Ochiohu community ($n = 169$) and Ogobia community ($n = 199$) participated in the face-to-face interviews. Trained research assistants assessed each household on presence of a person with epilepsy. All households were asked whether they regularly consumed pork. The person interviewed was asked whether he or she knew the causes of epilepsy and if so, what was considered the cause of epilepsy. Data on acceptance of and attitudes toward PWE and beliefs on epilepsy treatment were also collected.

If a person with epilepsy was found, his or her age and gender were registered. The potential cause of epilepsy was also determined. Because age was not always exactly known, we used the following age groups in years: 7—14, 15—24, 25—34, 35—44, 45—54 and 55 or older. Children six years and below were excluded from our study to prevent inflation of the prevalence due to febrile convulsions which are very common in the two study areas.

Epilepsy in developing countries has been associated with multiple causes, most importantly parasitic diseases, poor antenatal care, febrile seizures or a family history of febrile seizures, head injury, intracranial infections of bacterial or viral origin, toxic agents and hereditary factors (Senanayake

Figure 1 The geographic locations of the two study populations in Nigeria: Ochiohu community in Izzi, Ebonyi state and Ogobia community in Otukpo, Benue state.

and Román, 1993; Edwards et al., 2008; Ngugi et al., 2013). A case control study conducted in Nigeria reported febrile convulsions and head trauma as major cause for epilepsy (odds ratios >10; (Ogunniyi et al., 1987)). A more recent study among Nigerian Africans identified trauma and recurrent childhood febrile convulsions as the commonest causes of epilepsy (Ogunrin et al., 2013). In our questionnaire we therefore scored the following potential causes of epilepsy: prolonged labor, fever during pregnancy mother, neonatal trauma, birth asphyxia, neonatal jaundice or convulsion at 6 years and below, native herbs usage during pregnancy, head injury and a history of meningitis. To ensure that the correct obstetric and infantile history of PWE was obtained, we tried to interview the mother. In her absence the interview was done with the father or the most senior member of the household.

Pretesting and data analysis

Questionnaires were pilot-tested in two representative regions in Ebonyi state: Ohatekwe and Ugwuachara village. Pre-test results were discussed with the research assistants and modifications to the questionnaire were made if necessary. All research assistants were native speakers. The study was performed in September and November 2007. Epi info (CDC, version 3.3.2, 2005) was used to analyze the data collected with the questionnaires.

Proportions and their 95% confidence intervals (CIs) were calculated in *R* (www.r-project.org). More specifically, we used the 'score confidence interval' for binomial proportions as first discussed in Wilson (1927). This formulation has been recommended for use with nearly all sample sizes and parameter values (Wilson, 1927). For mathematical formulas we refer to (Agresti and Coull, 1998). Differences between communities were tested using standard χ-square calculations. All χ-square calculations had one degree of freedom (that is, two groups, the rural and semi-urban, are compared per calculation). A p-value <0.05 was considered significant.

Focus group discussions

Focus group discussions were conducted to elicit familiarity with, understanding of, and attitudes toward PWE. The groups were representative for the community. They included at least an elderly man and woman, a clergy, a local government councilor, a traditional birth attendant and a representative from the youth. Focus group discussions were held with ten individuals at each location.

Results

Epilepsy prevalence

The survey included 169 households in the Ochiohu community and 199 in the Ogobia community. Table 1 summarizes the number of households with at least one person suffering from epilepsy and the total number of individuals with epilepsy. In the Ochiohu community 26% [CI: 20—33] of all households had at least one person with epilepsy. This was 13.1% [CI: 9—19] in the Ogobia community. The epilepsy prevalence was 20.8 per 1000 [CI: 15.7—27.4] in the Ochiohu and 4.7 per 1000 [CI: 3.2—6.9; $p < 0.0001$] in the Ogobia community. The prevalences for the different age categories are shown in Table 2.

Potential causes for development of epilepsy

Potential causes for the epilepsy are summarized in Table 3. Most PWE had convulsion early in their life (<6 years), 81.4% [CI: 66.1—91.1] in the Ochiohu and 88.5% [CI: 68.7—97] in the Ogobia community. More than half of all mothers used herbs

Table 1 Community characteristics. CI: 95% confidence interval.

Community	Population	Households	Households with at least one person with epilepsy					Epilepsy prevalence					
			Total	CI total	%	CI %	χ^2	*p*-value	Total	CI total	per 1000	CI per 1000	χ^2	*p*
Ochiohu	2500	169	44	[33.4–56.5]	26.0	[20–33]	6.09	0.002	52	[39.3–68.5]	20.8	[15.7–27.4]	46.35	<0.0001
Ogobia	6000	199	26	[17.7–37.3]	13.1	[9–19]			28	[19.2–41.4]	4.7	[3.2–6.9]		

Table 2 People with epilepsy stratified by age.

Age (years)	Community			
	Ochiohu		Ogobia	
	Total	%	Total	%
7–14	16	30.8	15	53.6
15–24	22	42.3	11	39.3
25–34	9	17.3	1	3.6
35–44	3	5.8	1	3.6
45–54	2	3.8	0	0
Combined	52	100	28	100

during pregnancy in both communities. In the Ogobia community, fever by the mother during pregnancy was reported in 63.6% [CI: 40.8–82]. This was significantly lower in the Ochiohu community: 23.1%, $p = 0.004$. Prolonged labor and neonatal trauma were also identified as potential causes for epilepsy. In addition, several PWE had a history of meningitis, namely 9.5% [CI: 3.1–23.5, Ochiohu] and 25% [CI: 10.6–47.1, Ogobia].

Eighty percent of PWE consumed pork in the Ochiohu and 48% in the Ogobia community. Similar differences in pork consumption were found at household level (Table 4). More households ate pork in the Ochiohu community [77.1%, CI: 69.6–83.2]. This was significantly higher as compared to the Ogobia community [38.7%, CI: 31.8–45.9]: $p < 0.0001$.

Familiarity and understanding of and attitudes toward PWE

The perceived causes of epilepsy for both communities are shown in Table 5. Heredity was important in the causation of epilepsy in the Ochiohu community, whereas high fever was thought to be the major cause of epilepsy in Ogobia community. On the whole, medical factors were often thought to be the cause of epilepsy.

The belief whether epilepsy is treatable was more prevalent in the Ochiohu community ($p < 0.0001$), Table 6. Potential places for the treatment of epilepsy, mentioned by the respondents are summarized in Table 7. In the Ogobia community more people mentioned to go to the hospital for treatment of epilepsy, namely 93.3%. This was lower in the Ochiohu community (78.8%, $p = 0.05$).

The number of households that consider PWE to be socially accepted in the community is listed in Table 8. People in the Ogobia community more readily accepted PWE as compared to respondents from the Ochiohu community ($p = 0.006$).

The attitudes toward PWE are summarized in Table 9. In the Ochiohu community 78.6% [CI: 68.9–86] thought that PWE were isolated. This was much lower (48.3%; $p < 0.0001$) in the Ogobia community. In the Ochiohu community 6.1% [CI: 2.5–13.4] thought that PWE were ostracized. In the same community marriage was thought to be doubtful. Avoidance of PWE was found in the Ogobia community in 30% [CI: 19.2–43.4]. Fear for PWE was also present. In contrast with the ideas on isolation, avoidance and fear, employment of PWE was not considered to be a problem.

Table 3 Potential epilepsy causes in identified people with epilepsy. CI: 95% confidence interval.

Potential cause	Community									
	Ochiohu				Ogobia				χ^2	p
	Total	CI total	%	CI %	Total	CI total	%	CI %		
Native herbs during pregnancy mother	25	[18.3—30.7]	62.8	[45.8—76.8]	11	[6.4—15.5]	52.4	[30.3—73.6]	0.24	0.62
Fever during pregnancy mother	9	[4.6—15.5]	23.1	[11.7—39.7]	14	[9—18]	63.6	[40.8—82]	8.20	0.004
Prolonged labor	11	[6.1—17.6]	28.2	[15.5—45.1]	9	[4.7—14.1]	39.1	[20.5—61.2]	0.37	0.54
Neonatal trauma	15	[9.3—21.5]	39.5	[24.5—56.5]	6	[2.6—11.1]	27.3	[11.6—50.4]	0.45	0.50
Birth asphyxia	3	[0.8—8.6]	7.7	[2—22]	3	[0.8—8]	12.5	[3.3—33.5]	0.04	0.85
Neonatal jaundice	5	[1.9—10.9]	13.5	[5.1—29.6]	6	[2.6—10.9]	30	[12.8—54.3]	1.33	0.25
Convulsion at 6 years and below	35	[28.4—39.2]	81.4	[66.1—91.1]	23	[17.9—25.2]	88.5	[68.7—97]	0.19	0.66
Head injury	8	[3.8—14.6]	18.6	[8.9—33.9]	4	[1.3—9.2]	16	[5.3—36.9]	0.00	0.95
Meningitis	4	[1.3—9.9]	9.5	[3.1—23.5]	6	[2.5—11.3]	25	[10.6—47.1]	1.77	0.18

Table 4 Pork consumption in both communities. CI: 95% confidence interval.

Community	Eats pork					
	Total	CI total	%	CI %	χ^2	p
Ochiohu	121	[109.2—130.7]	77.1	[69.6—83.2]	50.37	<0.0001
Ogobia	75	[61.8—89.1]	38.7	[31.8—45.9]		

Table 5 Perceived causes of epilepsy. CI: 95% confidence interval.

Perceived cause of epilepsy	Community									
	Ochiohu				Ogobia				χ^2	*p*-value
	Total	CI total	%	CI %	Total	CI total	%	CI %		
Cerebral malaria	3	[0.8—8.3]	10.0	[2.6—27.7]	0	—	0.0	—	—	—
High fever	3	[0.8—8.3]	10.0	[2.6—27.7]	5	[2.4—7.6]	50.0	[23.7—76.3]	5.21	0.02
Stroke	1	[0.1—5.7]	3.3	[0.2—19.1]	0	—	0.0	—	—	—
Frequent convulsion	3	[0.8—8.3]	10.0	[2.6—27.7]	3	[0.8—6.5]	30.0	[8.1—64.6]	1.05	0.31
Infection	2	[0.3—7.1]	6.7	[1.2—23.5]	0	—	0.0	—	—	—
Stomach ache	1	[0.1—5.7]	3.3	[0.2—19.1]	0	—	0.0	—	—	—
Evil people	7	[3.2—12.8]	23.3	[10.6—42.7]	0	—	0.0	—	—	—
Evil spirit	2	[0.3—7.1]	6.7	[1.2—23.5]	0	—	0.0	—	—	—
Hereditary	8	[3.9—13.9]	26.7	[13—46.2]	2	[0.4—5.6]	20.0	[3.5—55.8]	0.00	1

Table 6 Perception on treatment of epilepsy in the Ochiohu and Ogobia communities. CI: 95% confidence interval.

Community	Considers epilepsy treatable					
	Total	CI total	%	CI %	χ^2	*p*-value
Ochiohu	106	[93.6—117]	68.4	[60.4—75.5]	61.70	<0.0001
Ogobia	51	[39.5—64.4]	25.9	[20—32.7]		

Table 7 Places where epilepsy can be treated as mentioned in the Ochiohu and Ogobia communities. CI: 95% confidence interval.

Places to treat	Community									
	Ochiohu				Ogobia				χ^2	*p*-value
	Total	CI total	%	CI %	Total	CI total	%	CI %		
Herbalist/native doctor	18	[11.3—27.3]	17.3	[10.8—26.2]	3	[0.8—8.7]	6.7	[1.7—19.3]	2.12	0.15
Hospital	82	[72.3—89.4]	78.8	[69.5—86]	42	[36.3—44.2]	93.3	[80.7—98.3]	3.74	0.05
Prayer house	4	[1.3—10.5]	3.8	[1.2—10.1]	0	—	0.0	—	—	—

Table 8 The number of households that consider people with epilepsy to be socially accepted in the Ochiohu and Ogobia communities. CI: 95% confidence interval.

Community	Social acceptance					
	Total	CI total	%	CI %	χ^2	*p*-value
Ochiohu	55	[43.5—67.6]	35.7	[28.3—43.9]	7.58	0.006
Ogobia	100	[85.9—114]	51.0	[43.8—58.2]		

Table 9 Attitudes toward people with epilepsy in the Ochiohu and Ogobia communities. PEW: people with epilepsy.

Attitudes toward people with epilepsy	Community									
	Ochiohu				Ogobia				χ^2	*p*-value
	Total	CI total	%	CI %	Total	CI total	%	CI %		
PWE should be abandoned	0	—	0.0	—	3	[0.8–8.9]	5.0	[1.3–14.8]	—	—
PWE should be avoided	0	—	0.0	—	18	[11.5–26]	30.0	[19.2–43.4]	—	—
PWE should be buried separately	0	—	0.0	—	1	[0.1–6.1]	1.7	[0.1–10.1]	—	—
PWE are thought to be disgusting	0	—	0.0	—	1	[0.1–6.1]	1.7	[0.1–10.1]	—	—
PWE are feared	0	—	0.0	—	5	[1.9–11.5]	8.3	[3.1–19.1]	—	—
PWE should be kept in isolation	77	[67.5–84.2]	78.6	[68.9–86]	29	[21.2–36.9]	48.3	[35.4–61.5]	14.07	<0.0001
PWE should not marry	9	[4.5–16.8]	9.2	[4.5–17.2]	0	—	0.0	—	—	—
PWE should be treated as people with leprosy	1	[0.1–6.2]	1.0	[0.1–6.4]	0	—	0.0	—	—	—
PWE should not be employed	1	[0.1–6.2]	1.0	[0.1–6.4]	0	—	0.0	—	—	—
PWE should be ostracized	6	[2.5–13.1]	6.1	[2.5–13.4]	0	—	0.0	—	—	—
PWE should be rejected	2	[0.3–7.7]	2.0	[0.4–7.9]	2	[0.3–7.5]	3.3	[0.6–12.5]	0.00	0.98
PWE should be sent away	0	—	0.0	—	1	[0.1–6.1]	1.7	[0.1–10.1]	—	—
PWE are thought to be unclean	2	[0.3–7.7]	2.0	[0.4–7.9]	0	—	0.0	—	—	—

Focus group discussions in the rural community

In Ochiohu, Ebonyi state, epilepsy is known as *Ndaafu*. Participants mentioned that epilepsy is: (i) the result of witchcraft; (ii) transferred from parents to their offspring; (iii) caused by transmission through blood; (iv) a contagious disease. A traditional birth attendant among the group believed that birth trauma is one of the major causes of epilepsy in the Ochiohu community. Her thinking was that in the earlier days, during delivery—which takes place in the barn at home—the baby typically falls to the ground. In addition, the traditional birth attendants did not use gloves to take deliveries. However, during recent trainings, which they have received from a primary health service program, they have learned that babies should not be allowed to fall to the ground and gloves should be used during deliveries. She thought that this training resulted in a remarkable drop in the number of children developing epilepsy.

During the discussion on attitude toward PWE two issues became clear, namely (i) there is social seclusion of PWE because the community thinks that epilepsy is a contagious disease and (ii) PWE will not marry unless both partners have epilepsy.

The participants believed that epilepsy could be treated by both modern and traditional methods, though they preferred treatment with modern medicine. They referred to the treatment of PWE by the community-based rehabilitation program that is active in their area using antiepileptic drugs. Their argument was that a person who had suffered from epileptic attacks and who is now taking drugs has stopped having attacks, whereas the one who is taking native herbs do not show improvements. The respondents believed that provision of antiepileptic drugs and the construction of a health center would greatly help PWE and the community in general. A few however believed that native medicine also have a place in the treatment of PWE.

Focus group discussions in the semi-urban community

In the focus group discussions in Ogobia ten people (three women) were involved in the discussions. Epilepsy is known as *Ejighano* in their local dialect. The participants felt that epilepsy is common in their community. They gave the following as suspected causes: (i) fever and convulsions; (ii) witchcraft; (iii) a natural cause, that is, some people are just born with it; (iv) it is transferred from parents to their offspring (hereditary, not contagious); and (v) if you inherit properties from someone who suffered from epilepsy you will also get epilepsy. The latter cause of epilepsy may be prevented if a native medicine man performs burial rites for the dead PWE and if he takes away their property and burns it. Burial of PWE far away from home also prevents you from getting epilepsy.

Some of the identified practices toward PWE included: (i) people do not eat together with, or sleep together with, nor wear the same clothes as PWE; (ii) there is no marriage with PWE or with their families; (iii) herbalists treat the PWE for their recurrent seizures. This treatment involves the making of scarification marks and the application of the ashes of burnt wall-gecko (lizard) to these marks; and (iv)

family members could touch PWE during an epileptic attack without getting epilepsy. However, if someone not related to PWE touch them the person becomes infected with epilepsy.

The respondents believed that drugs could control epilepsy as long as the PWE take them. In addition, the group strongly believed that drug treatment and special clinics, when made available to them, would reduce the prevalence and burden of epilepsy in their community.

Discussion

In this study we estimated the prevalence of epilepsy in a rural and semi-urban community in Nigeria. The prevalence was high in the rural community. Causes that might possibly be contributory to the prevalence of epilepsy are poor obstetric practices, frequent febrile convulsions, head trauma and meningitis. Neurocysticercosis might also have been responsible for the high prevalence. In both communities people were not well informed about the cause of epilepsy. We found the attitudes toward PWE worrisome. Nevertheless, members both communities would like to see the establishment of an epilepsy control program in their region.

A previous study estimated the prevalence of epilepsy, 25 year ago, in a town in south-west Nigeria to be 5.3 per 1000 (Osuntokun et al., 1987). This number is in line with the prevalence we found in the semi-urban community: 4.7 per 1000.

The much higher prevalence in the rural Ochiohu community, 20.8 per 1000, is in line with prevalence data estimated in a recent systematic review using multiple sub-Saharan epilepsy studies (Ngugi et al., 2010). Ngugi et al. reported a prevalence of 5.8 per 1000 (5th—95th percentile range 2.7—12.4) in urban studies and 15.4 per 1000 (4.8—49.6) for rural studies. A remarkable difference with the systematic review is that studies involving all ages or only adults showed higher estimates than pediatric studies (Ngugi et al., 2010). We found most of the epilepsy in the younger age group. This is perhaps caused by differences in underlying etiology or population characteristics.

The high rural prevalence may relate to higher frequency of adverse perinatal events such as birth trauma, as also found in other sub-Saharan areas (Burton et al., 2012). It may also be attributable to parasitic diseases. In particular onchocerciasis has been linked to rural epilepsy (Ngugi et al., 2013). Onchocerciasis is endemic in the Ochiohu community. The high rural epilepsy prevalence might also be caused by neurocysticercosis. Consumption of pork infected with *Taenia solium* could predispose people to epilepsy and is one of the main causes of acquired epilepsy in endemic areas in low- and middle-income countries around the world, including sub-Saharan Africa (Preux and Druet-Cabanac, 2005). As much as 77.1% of households in the rural Ochiohu reported eating pork and 80% of PWE reported eating pork. This finding corroborates with results from a recent meta-analysis using eleven studies conducted in Africa that found a significant link between cysticercosis infestation and the occurrence of epilepsy (Quet et al., 2010). Although we did not perform microbiological tests on stool in this study population, it is likely that cysticercosis is present in the Ochiohu community. In the Ochiohu community, pigs roam freely to forage for food which potentially exposes them to *Taenia solium* eggs in fecal contamination as latrines are limited and open defecation is common practice. These pigs are typically slaughtered without attention to hygienic measures. The exact prevalence of cysticercosis is however unknown and requires further research.

What is known from our data is that neurocysticercosis awareness was very low. This is not surprising as poor knowledge regarding the spread of taeniasis and neurocysticercosis has also been found in other areas endemic for cysticercosis (Girotra et al., 2011). Community health education might prevent taeniasis and cysticercosis and improve the knowledge and practices of the community (Alexander et al., 2012).

Analysis of our data revealed that more than eighty percent of the members in the rural and semi-urban community link epilepsy with febrile convulsion and convulsion occurring early in life. It is estimated that about three percent of children who have febrile convulsions go on to develop epilepsy in later life (Dube et al., 2007). The high percentage of febrile convulsions observed in the rural Ochiohu community might be attributed to the poor management of febrile illness itself and the associated convulsion. A prospective cohort study is needed to link febrile convulsions to the development of epilepsy.

Evil people and evil spirits were an important perceived cause of epilepsy. Evil persons are thought to inflict diseases like epilepsy on their fellow human beings through witchcraft. Though this was not mentioned as a cause of epilepsy in the semi-urban area in the questionnaires, the focus group discussion participants were quick to mention that this is a common cause of epilepsy. These ideas are not exclusive for our study population. About 22% of Nigerian teachers considered epilepsy to be caused by spirits (Ojinnaka, 2002) which was approximately similar to the 27.7% found among teachers from a different state in Nigeria (Sanya et al., 2005). Moreover, epilepsy was commonly attributed to a spiritual attack, witchcraft and other supernatural causes in focused group discussions among Yoruba women in Nigeria (Komolafe et al., 2011). Also in other African countries such as Senegal, 28.7% of teachers considered epilepsy to be supernaturally afflicted (Ndour et al., 2004); among preparatory students in North Ethiopia 33% believe in evil spirits to cause epilepsy (Vivas et al., 2012). Clearly, the perceived origin of epilepsy is considered multidimensional in nature. This should be taken into account in community interventions and educational programs that aim to reduce stigma and discrimination of PWE.

The majority of the people in the rural setting believed that epilepsy is treatable. The contrary was the case in the Ogobia community. This might be the result of an existing community epilepsy program that treats PWE in Ochiohu using low cost phenobarbital. There is no such program in Ogobia. It is therefore possible that the Ochiohu community has seen the response of the people being treated for epilepsy and therefore has faith in the efficacy of antiepileptic treatment. During the focus group discussions, most of the people in Ochiohu knew where a person with epilepsy could obtain treatment, whereas only few in Ogobia knew a place for such treatment.

Cultural values affect people's health-seeking strategies. If people see epilepsy as caused by something that is not natural or biomedical, then treatment through western medicine may not be sought as reported previously (Bartolini et al., 2011). Such beliefs may result in PWE to seek treatment from traditional or faith healers.

A greater number of people in the Ogobia community mentioned that PWE are well accepted in the community in contrast to only 35.7% in the Ochiohu community. However, as can be seen in Table 9, almost 80% of the community members mentioned that PWE are kept in isolation. This finding was collaborated during the focus group discussions. The extent of the discrimination is that people do not eat or drink with PWE. Marriage with PWE is also out of the question. Worst of all, in the Ogobia community, PWE are not even buried together with non-epileptic individuals. We think, based on the focus group discussions that those thoughts are related to fear of being infected with epilepsy if someone has any contact with a person with epilepsy. These findings are in line with multiple studies conducted in Africa. For instance, epilepsy has been considered a contagious disease or a mental illness in Nigeria (Ojinnaka, 2002; Alikor and Essien, 2005; Sanya et al., 2005), Senegal (Adotevi and Stephany, 1981; Ndour et al., 2004), Burkina Faso, Tanzania (Rwiza et al., 1993; Matuja and Rwiza, 1994) and Cameroon (Njamnshi et al., 2009a,b,c,d). Based on these data and our results we expect that PWE face multiple social and economical challenges and stigma reduction programs are an asset.

Our study has limitations. Door-to-door surveys are considered to be the optimum method for obtaining epilepsy prevalence data (Paul et al., 2012). However, epidemiological studies in epilepsy remain challenging as identification of PWE relies on disease history recounted by individuals rather than definitive tests (Sander and Shorvon, 1987). This leaves opportunities for misinterpretation as there is a wide range of seizure types, some of which present vary differently to the stereotypical tonic—clonic seizure. Individuals could also deny having experienced or witnessed seizures due to stigma.

Second, due to restricted financial resources we only included a single rural and single semi-urban community in our study. Inclusion of more communities would have given a better estimation of the true prevalence of epilepsy in both Ebonyi and Benue states. Third, information on potential causes was only collected in households with a person with epilepsy. Whether these are true risk factors remains to be determined, as we lack a control group. The calculation of odds ratios is therefore not possible. A proper case—control study is needed to verify the true risk profiles of our identified potential causes.

Despite these limitations we think that our data increases the understanding of believes and misbelieves concerning epilepsy in rural Ebonyi state and surrounding areas. Our study sheds new light on the public health problem of epilepsy in Nigeria. The prevalence of epilepsy is so high in the rural setting that it may be declared a medical emergency. Establishing a community based intervention to treat epilepsy with low cost antiepileptic drugs and the initiation of educational and social programs may have a positive impact on the lives of the PWE in Nigeria. In the long run this may help to reduce the stigma and social discrimination associated with the epilepsy.

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