



## Understanding of and attitudes towards people with epilepsy among community-based rehabilitation volunteers in Guinea-Bissau



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### ABSTRACT

**Background:** Community-based epilepsy care programs improve access to epilepsy treatment in resource-poor settings. Community volunteers are important to these services. Most studies on familiarity with, understanding of, and attitudes towards people with epilepsy (PWE), however, ignore these volunteers.

**Methods:** We explored these issues among 15 community volunteers involved in a community-based rehabilitation child epilepsy service recently initiated in Guinea-Bissau using face-to-face interviews.

**Results:** We found that the volunteers had a reasonable understanding of epilepsy, moderate attitudes towards PWE, and a good understanding of difficulties PWE encounter in society.

**Conclusion:** Evaluation of understanding and attitudes of community volunteers may be useful to improve low-cost community-based epilepsy programs. A correct understanding of epilepsy among community volunteers may increase effective treatment of and support to children with epilepsy through community-based epilepsy programs.

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## 1. Introduction

Epilepsy is a common and chronic neurodisability that affects over 60 million people worldwide [1,2]. The vast majority lives in low- and middle-income countries [1,3]. Three-fourths of people with epilepsy in these settings remain untreated; this is known as the treatment gap [4]. People with disabilities in these areas are among the most vulnerable in any society; those with active epilepsy are particularly vulnerable as they are often stigmatized and excluded [5,6].

Bridging the treatment gap and reducing the burden of epilepsy in sub-Saharan Africa remain challenging because of social and political instability, poverty, stigmatization, poor health care system infrastructure, scarcity of trained medical personnel, and a severe shortage of epilepsy specialists [7]. There is, however, increasing evidence that community-based epilepsy care programs improve access to epilepsy treatment in resource-poor settings [8,9]. The World Health Organization specifically advocates the use of community-based rehabilitation

(CBR) services to equalize the social integration of people living with a disability, including people with epilepsy (PWE) [10–12]. A key element in the delivery and success of these CBR epilepsy services is the availability of community volunteers [13].

Despite their importance, community volunteers remain ignored in studies on familiarity with, understanding of, and attitudes towards PWE. We explored these issues among the community volunteers involved in a CBR child epilepsy service recently initiated in Guinea-Bissau, one of the poorest countries in sub-Saharan Africa and considered a failed state [14].

Insights obtained may be used to update the baseline CBR training of new volunteers and could improve the biomedical CBR service in reducing the burden of epilepsy in children in Guinea-Bissau and other sub-Saharan countries.

## 2. Methods

### 2.1. CBR child epilepsy service: study setting

Guinea-Bissau is a small coastal country in West Africa, between Senegal to the North and the Republic of Guinea in the East and South.

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It has about 1.5 million inhabitants. The country has a large ethnic diversity with more than thirty groups, including the Balanta, Bijagu, Papel, Fula, Mandinga, and Manjaco, each with a distinct language and set of traditions. About 45% of the population, mainly Fulani or Mandinga, are Muslims. The Balanta, Manjaco, and Papel make about half of the population and follow either Animisms or Christianity.

Guinea-Bissau is one of the poorest countries in the world. The Human Development Index, a composite index measuring average country achievement in three basic dimensions of human development (a long and healthy life, knowledge, and a decent standard of living), is 176 for Guinea-Bissau, a value higher than that in only 11 countries worldwide [15].

The country lacks basic healthcare facilities and has no neurological services. No single electroencephalography, computed tomography, or magnetic resonance imaging system is available, and no neurologist is known to work in the country [16]. No public health data are available [17]. No epilepsy prevalence data are available, but this is expected to be high because of the association of traditional pig rearing and poor sanitation that has been linked to neurocysticercosis and, subsequently, to epilepsy [18,19]. Traditional healing methods, including treatment for mental disorders and epilepsy, are common and popular, but little information is available about the outcome of these traditional healing approaches [20].

This cross-sectional study was carried out among community volunteers in Buba, which is the largest town in southern Guinea-Bissau, with a population of 6815 (2008 Census [21]). A CBR child epilepsy service was started there in 2011. This program includes community-based support for children living with epilepsy and their families and aims at increasing social support, reducing prejudice, and overcoming the erroneous beliefs that perpetuate stigma. Additional CBR services will be initiated in 2013/14 in the North and East of the country. This current study is pilot work done to help increase efficacy of new volunteer training. We plan to update our data if more community volunteers are available, and we will follow up on the existing volunteers.

## 2.2. CBR child epilepsy service: volunteers

The volunteers were selected from the community (after announcements in schools, churches, and community meetings) through interviews conducted in summer 2011. The selection was primarily based on motivation and enthusiasm to participate. They received ten days of baseline CBR training including one day devoted to neurodisability and epilepsy. Additional CBR training days are organized every month. Most of the CBR training is based on the public health manual 'Disabled Village Children' [22] and chapters from the 'Training in the Community for People with Disabilities' book [23]. The training focused on medical, social, and rehabilitational knowledge, attitudes, and skills among volunteers. Stereotypes about persons with a disability were challenged, and different approaches to disability were explained. During training, there was specific emphasis on stigma related to disability, and local beliefs, prejudices, and culture related to disabilities were discussed.

Each volunteer was assigned to a specific residential quarter of Buba. The volunteers were encouraged to visit all compounds in their quarter to identify children with disabilities. Potential cases are reported to the CBR center where diagnoses are established in conjunction with a CBR staff member. When a child is suspected of having epilepsy, the family is asked to keep a seizure diary. The community-based rehabilitation volunteers monitor antiepileptic drug compliance and adverse effects. Problems with the children are typically initially identified by the volunteers and reported to the CBR staff. The volunteers also play an important role in advocating for the children at schools and in the community.

Sixty children with disabilities living in Buba were known to the CBR staff at the time of this study (April and May 2012), of whom ten were treated for epilepsy with phenobarbital, and four kept seizure diaries.

## 2.3. Study sample, questionnaire, and data analysis

As the service started recently (2011), the number of volunteers is still small. We included all the community volunteers ( $n = 15$ ). Data were collected through face-to-face interviews using a semistructured questionnaire. This questionnaire was developed using qualitative information obtained from previous discussions with local CBR staff members and key informant interviews with a subset of volunteers. These qualitative data were thematically analyzed and aided the development of the questionnaire used for this study.

Following a pretest of the questionnaire, two local CBR staff members (DLT and BA), a trained local resident (AAN) and an epidemiologist (WMO), interviewed all the volunteers in the *lingua franca* Creole.

The final questionnaire comprised questions about familiarity with, knowledge of, and attitudes towards PWE and questions regarding sociodemographic information including age, gender, marital status, and level of education.

All checked and cleaned data were entered in a database. Proportions and their 95% confidence intervals for the sociodemographic characteristics and volunteers' responses were generated using SAS/STAT® version 9.2 (SAS Institute Inc., Cary, NC, USA).

## 2.4. Ethics

Prior to the interviews, the study aim was clearly explained to all the volunteers so that they could decline participation. They did not have to answer questions if they did not want to. Anonymity was obtained through the assignment of numbers during data collection. Ethical approval was obtained prior to data collection from the board of the community program Reabilitação com Base na Comunidade Jedidias, Buba, Guinea-Bissau.

## 3. Results

Of the 15 volunteers interviewed, all but one were ethnic Balantas (the remaining was Bijagu). Nine were male. Eleven were aged between 15 and 24 years, three were aged between 25 and 34 years, and one was older than 45 years. All the volunteers were Christian (*Evangeliku*). One was married. Two did not finish primary school, twelve had not completed secondary school, and one had completed secondary education. Fourteen were unemployed. None had epilepsy, but four had a family member with epilepsy, and six knew someone with epilepsy. One had a close friend with epilepsy. They all fully participated and answered all questions presented.

Knowledge that volunteers had about PWE is listed in Table 1. The majority did not consider epilepsy to be a contagious disease or a disease of the blood, neither did the majority consider epilepsy to be related to madness or learning disability.

Attitudes that volunteers had towards PWE are given in Table 2. We did not find strong negative feelings regarding contact with, marriage with, or being in the presence of a person with epilepsy. The majority would help a person having a seizure and would not be afraid. Not all, however, shared these ideas (2 volunteers).

**Table 1**

Knowledge about people with epilepsy among all volunteers ( $n = 15$ ). N: number of volunteers that answered yes. CI: confidence interval.

Question	N	Percentage (95% CI)
Can you see who has epilepsy just by watching them? [yes]	8	53% (27, 78)
Is epilepsy a contagious disease? [yes]	4	27% (9, 55)
Is epilepsy a blood disorder? [yes]	4	27% (9, 55)
Is foam from the mouth during a convulsion an infecting agent? [yes]	3	20% (5, 49)
Is mental retardation related to epilepsy? [yes]	5	33% (13, 61)
Do you think epilepsy is a form of insanity? [yes]	4	27% (9, 55)

**Table 2**  
Attitudes towards people with epilepsy among all volunteers. N: number of volunteers that answered yes. CI: confidence interval.

Question	N	Percentage (95% CI)
Would you refuse if your child wants to marry a person with epilepsy? [yes]	5	33% (13, 61)
Would you marry someone with epilepsy? [yes]	6	40% (17, 67)
Are people uncomfortable with a person with epilepsy? [yes]	8	53% (27, 78)
Would you let your child play with someone who has epilepsy? [yes]	13	87% (58, 98)
If you see someone with a seizure, would you help him? [yes]	13	87% (58, 98)
Do you avoid people with epilepsy? [yes]	3	20% (5, 49)
Would you share a drink with someone who has epilepsy? [yes]	6	40% (17, 67)
Would you be afraid to sit beside someone with epilepsy? [yes]	2	13% (2, 42)

In terms of religious ideas and epilepsy, two-thirds of volunteers agreed that epilepsy was caused by ruling spirits, locally known as *irans* (Table 3). They relate epilepsy (called *kai di attaki*, falling sickness or *durba kabesa*, or knocking down the head) to demonic possession.

Four of the fifteen considered epilepsy a punishment for sins in general (i.e., sins conducted by family, parents, or the community). Only two linked epilepsy with someone's personal fault. One Guinean belief is that an evil spirit will enter a family member if, after death, a person possessed by the spirit is buried with visible grief or nicely dressed. The majority thought that no distinction should be made in ceremonial procedures during a funeral whether or not the dead person had epilepsy.

Common beliefs about epilepsy and treatment options are listed in Table 4. Several volunteers believed that epilepsy hinders friendship and causes PWE to be treated cruelly by family and community members, and they considered epilepsy a disgraceful condition. In addition, several volunteers emphasized that these answers related only to someone with active epilepsy. The screaming, violent movements, loss of consciousness, and incontinence as a result of a convulsive seizure were considered disgraceful. Half of them believed that PWE feel unhappy and also have behavioral problems.

Eleven of the fifteen volunteers believed that Western medicine is effective for epilepsy, while nursing, rehabilitation, and visits to the hospital in Bissau were also mentioned. One stated that egg consumption was an effective treatment, while one believed that traditional medicine was helpful. Two volunteers believed that PWE should not consume palm oil (from the oil palm *Elaeis guineensis*) as this could trigger seizures.

Questions regarding education and employment are presented in Table 5. Most thought that PWE could function normally in society, but that special schools were needed for children with epilepsy. Employment was not considered a problem for people with epilepsy, but not every profession was considered feasible for them.

#### 4. Discussion

This study is a starting point in identifying the understanding of and attitudes towards PWE among community volunteers, a previously unexplored topic. In a recently initiated CBR child epilepsy service in Guinea-Bissau, we found that the volunteers have a reasonable

**Table 3**  
Religion and epilepsy among all volunteers. N: number of volunteers that answered yes. CI: confidence interval.

Question	N	Percentage (95% CI)
Is epilepsy caused by spirits? [yes]	10	67% (39, 87)
Is epilepsy a punishment for sins? [yes]	4	27% (9, 55)
Is it someone's fault if he or she has epilepsy? [yes]	2	13% (2, 42)
Should the funeral of people with epilepsy be similar to other funerals? [yes]	13	87% (58, 98)

**Table 4**  
Beliefs related to people with epilepsy among all volunteers. N: number of volunteers that answered yes or gave an open answer. CI: confidence interval.

Question	N	Percentage (95% CI)
Is it hard to make friends when you have epilepsy? [yes]	5	33% (13, 61)
Should a person with epilepsy always be with someone? [yes]	10	67% (39, 87)
Do you think people with epilepsy are approached cruelly? [yes]	7	47% (22, 73)
Do you think being a person with epilepsy is a disgraceful condition? [yes]	6	40% (17, 67)
Do you think people with epilepsy feel unhappy? [yes]	8	53% (27, 78)
Does everyone with epilepsy have behavioral problems? [yes]	7	47% (22, 73)
People with epilepsy can be treated with ... [open question]		
Modern drugs, tablets	11	73% (45, 91)
Nursing, rehabilitation, or hospital care	3	20% (5, 49)
Prayer	1	7% (0, 34)
Consumption of eggs	1	7% (0, 34)
Traditional medicine	1	7% (0, 34)
Nothing	2	13% (2, 42)

understanding of epilepsy, moderate attitudes towards PWE, and a good understanding of difficulties PWE encounter in society.

There is evidence that community-based epilepsy care improves access to epilepsy treatment. Experiences at two community-based programs in rural China [8] and in Brazil [9] suggested that epilepsy could be effectively treated at a community level with low-cost antiepileptic drugs by health care workers with only basic training. People with epilepsy also need social support and help to reintegrate in society. To that aim, CBR programs are considered essential in low- and middle-income countries [10]. Almost all governments and nongovernmental organizations in developing countries use a CBR approach to work with disabled people, including those running epilepsy services [24]. The success of a CBR program is, however, dependent on the commitment of community volunteers who are often misunderstood and ignored in studies on the behavioral aspects of epilepsy. The number of volunteers in this study is small, but it is of interest to compare our results with general findings from other sub-Saharan countries.

The understanding of epilepsy among the volunteers was reasonable compared with recent work from other communities (for review see [25]). In these communities, knowledge levels were very limited, and frequent beliefs are about epilepsy as a mental problem or an emotional disturbance. Rural communities also often perceive epilepsy as a feared disorder because of its relation with sorcery and evil spirits.

Respondents often consider epilepsy a contagious disease, a mental illness [26–37], or a kind of insanity [26]. Knowledge of epilepsy

**Table 5**  
Ideas about education and employment of people with epilepsy among all volunteers. N: number of volunteers that answered yes. CI: confidence interval.

Question	N	Percentage (95% CI)
Can people with epilepsy function normally in society? [yes]	11	73% (45, 91)
Should there be a special school for children with epilepsy? [yes]	13	87% (58, 98)
Do you think people with epilepsy should be employed? [yes]	12	80% (51, 95)
Would you hire someone with epilepsy to work at your home? [yes]	9	60% (33, 83)
Is failure at school related to epilepsy? [yes]	4	27% (9, 55)
Do you think people with epilepsy can be as successful as others? [yes]	6	40% (17, 67)
People with epilepsy could be employed as ...		
Physician	6	40% (17, 67)
Policeman	7	47% (22, 73)
Pilot	1	7% (0, 34)
School teacher	7	47% (22, 73)
Football player	10	67% (39, 87)
Fisherman	1	7% (0, 34)
Carpenter	4	27% (9, 55)
Salesman	9	60% (33, 83)

was poor to very poor among teachers in Nigeria [27], Senegal [30], and Burkino Faso [38], with less than 30% of knowledge-related questions correctly answered.

We found that 13 of 15 would let their child play with a child with epilepsy, while a similar number would help a person during a convulsion, and 12 would not avoid PWE. This is contrasted by, for instance, Nigerian teachers who, despite a fairly high level of education, had negative attitudes and beliefs towards PWE [28].

Religion plays an important role in Guinea-Bissau in coping with and understanding diseases. Two-thirds of the volunteers considered *irans* (spirits) causally linked to epilepsy, although this was not considered the fault of PWE. Despite the link with *irans*, volunteers thought that PWE should have similar funerals to individuals without epilepsy. The attribution of epilepsy to spiritual attacks, witchcraft, and supernatural affliction is well known from previous studies in Senegal [30], Ethiopia [26], and Nigeria [28,29,39]. This was also found among clerics [40], teachers [41], health care workers [42] and police officers in Zambia [43], and people from two communities in Cameroon [34,44].

Volunteers in our study suggested the need for special schools for children with epilepsy. This erroneous belief is comparable with that found among Nigerian and Senegalian teachers [27,30]. Our results on the employment of PWE are slightly more positive. Of the volunteers, twelve (80%) thought that PWE should be employed, and nine (60%) would hire someone with epilepsy to work at their house. These numbers are approximately similar to those from studies in other African countries, Ethiopia [26], Zambia [42], and Cameroon [34,36,44].

In summary, in relation to knowledge of and attitudes towards PWE among sub-Saharan countries, CBR volunteers in Guinea-Bissau do reasonably well in terms of knowledge and probably better in terms of attitudes.

These results are surprising as the volunteers had a basic training only, and PWE in sub-Saharan Africa are, in general, highly stigmatized and prone to exclusion from society. This may be due to Guineans' distinct colonial history or large ethnic mixing. It may also relate to the community members being willing to volunteer (as distinct from the general population) perhaps because a relative or friend has epilepsy. A third aspect that may explain our findings might be the effectiveness of the basic CBR training mandatory to every community volunteer in combination with regular visits to compounds with children that have active epilepsy. Percipient and close contact with these children may help them conclude that epilepsy is not contagious. The dramatic reduction in seizure load in most children starting to use phenobarbital could also be very helpful in the formation of a more positive view on epilepsy.

## 5. Conclusion

Epilepsy is a common public health problem in Guinea-Bissau. Effective treatment of and support to children with epilepsy through a CBR program is a sustainable and low-cost solution, but critically depends on the community volunteers. Evaluation of the understanding and attitudes of these volunteers is useful in improving community-based medical treatment. We suggest including monitoring of volunteers in current and future community-based epilepsy care programs.

## Conflict of interest statement

None of the authors have any conflict of interest in relation to this work to disclose.

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