



## Cultural beliefs among people with epilepsy or physical impairment in Guinea-Bissau: Differences and similarities



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### ABSTRACT

People living with a disability in sub-Saharan Africa have poorer health outcomes, lower educational successes, less economic participation, and higher levels of poverty than people without disability. Disability-inclusive development promotes the involvement of people with disabilities in programs that reduce these inequalities. This requires a good understanding of how individuals with disability perceive their condition.

In this study, we identified cultural beliefs among 31 individuals with epilepsy or physical impairment, known to a community-based rehabilitation service in Guinea-Bissau, using face-to-face interviews. We related these beliefs to religious background and type of disability.

We found poor knowledge of and attitudes towards disability among persons with epilepsy and physical impairment. Cultural beliefs were significantly shaped by religious background. Islamic respondents were more positive about their disability as compared to Christians and traditional believers.

A better understanding of cultural beliefs among people with disabilities may help to launch and adapt disability-inclusive community-based rehabilitation services.

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### 1. Introduction

People living with disabilities in sub-Saharan Africa are prone to stigma and social marginalization, particularly those with epilepsy [1–4]. Multiple studies have identified the knowledge of and attitudes towards people with epilepsy in this area [5]. However, results are based on nondisabled study populations such as clerics [6], teachers [7–9], police officers [10], health-care workers [11], and students [12–14]. An unanswered question is what people with disabilities in sub-Saharan Africa personally believe about their condition. No information is available on how they perceive their condition and if they fear isolation and discrimination. Whether their beliefs are shaped by religion, and if so, to what extent, is also unidentified. Moreover, how persons with epilepsy (PWE) compare to individuals with other disabilities in terms of personal beliefs is important information as well but remains a neglected area of research.

We explored these issues among individuals with a disability, who were registered to a community-based rehabilitation (CBR) program recently initiated in the Quinara region of Guinea-Bissau. We specifically compared PWE to individuals with a physical impairment and identified differences between religions.

The results obtained from this study may help in identifying important similarities and differences between people with a disability in terms of their beliefs and consequently increase the effectiveness of disability-inclusive community interventions.

### 2. Methods

#### 2.1. Study setting

Guinea-Bissau is a small coastal country located in West Africa, between the Republic of Senegal in the north and the Republic of Guinea in the east and south. It is one of the poorest countries in the world and has one of the lowest scores on the human development index, which is a composite score on the achievement in human development [15]. The country lacks basic health-care facilities, and proper public health information is not available. The country's prevalence of disability is unknown but is likely to be similar to that of the surrounding sub-Saharan regions, that is, 6 to 13% of the total population [16]. Guinea-Bissau has a large ethnic diversity with more than thirty ethnic groups, including the Balanta, Bijagu, Papel, Fula, Mandinga, and Manjaco, each with a distinct language and set of traditions. The Balanta, Manjaco, and Papel compose half of the population and adhere to traditional religions. About 45% of the population is Muslim, which is mostly represented by the Fula or Mandinga ethnicity. A minority of the population is Christian, either Roman Catholic or Evangelical. Traditional healing methods are

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popular among all ethnic groups and are commonly applied to people with physical impairments, mental disorders, and epilepsy. However, no scientific information is available about the outcome of these approaches [17].

## 2.2. Community-based rehabilitation program

In 2011, a CBR program was initiated in Buba, the largest town in southern Guinea-Bissau with an estimated population of 7000, in the Quinara area. Community-based rehabilitation programs are known for their effectiveness in stigma reduction by means of low-cost services [18,19]. This program includes community-based support to people living with disabilities and their families. The program's aim is to increase social support and reduce prejudice in the community in addition to introducing prevention and treatment strategies such as vitamin D distribution, antiepileptic drug therapy, and orthopedic surgery. A new CBR service will be initiated in 2014 in the north of the country. We plan to update our current findings using data from this additional service in the near future.

## 2.3. Group definition and data acquisition

More than sixty persons with disabilities living in Buba and surrounding villages were known to the CBR staff at the time of this study (April and May 2012). From these, we selected two groups: PWE ( $n = 15$ ) and individuals with an orthopedic disability ( $n = 16$ ). The PWE received phenobarbital to prevent recurrent seizures. 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. These qualitative data were thematically analyzed and used to develop the final questionnaire. Following a pretest of the questionnaire, two local CBR staff members (DLT and BA), a trained local resident (AAN), and an epidemiologist (WMO) conducted all interviews in the *lingua franca* Creole. The final questionnaire comprised both questions regarding sociodemographic information including age, gender, and religion and questions about cultural beliefs in relation to disability. All checked and cleaned data were entered in a database. Binary logistic regression was used to compare responses and calculate odds ratios (ORs) between Muslims, Christians, and traditional believers. A similar analysis was utilized to compare responses from the groups with epilepsy and physical impairment. Analysis was done in SAS (SAS/STAT® 9.2, SAS Institute Inc., Cary, NC, USA). Values of  $P < 0.05$  were considered statistically significant.

## 2.4. Ethics

Prior to the interviews, the study aim was clearly explained so that participation could be declined. 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

Table 1 shows the demographic data for the 31 study participants. Five ethnicities were represented, with the majority being ethnic Balanta (45%) or ethnic Fula (19%). Most participants were Muslim or Christian, comprising 45% and 39% of the sample, respectively.

In all PWE, the onset of epilepsy was during their childhood, except for two who developed spontaneous seizures during adolescence and adulthood. The PWE reported that seizures occur every hour (27%), every day (13%), every week (47%), or every month (7%). One person did not know the frequency. These frequencies were related to the time they did not yet receive phenobarbital but kept a seizure diary. The PWE were not affected by burns.

**Table 1**  
Characteristics of the 31 respondents.

	Number (%)
Age	
7–14 years	9 (29)
15–24 years	7 (22.6)
25–34 years	2 (6.5)
35–44 years	6 (19.4)
45+ years	7 (22.6)
Sex	
Male	17 (54.8)
Female	14 (45.2)
Ethnicity	
Fula	6 (19.4)
Balanta	14 (45.2)
Biafarda	9 (29)
Papel	1 (3.2)
Mandinga	1 (3.2)
Religion	
Traditional religion	5 (16.1)
Muslim	14 (45.2)
Christian (Evangelical)	10 (32.3)
Christian (Roman Catholic)	2 (6.5)

The disabilities in the group with physical impairment included both congenital musculoskeletal disabilities (e.g., *talipes equinovarus*) and acquired disabilities of the musculoskeletal system. The latter included leg deformation due to poliomyelitis or extensive osteomyelitis, severe *genu valgum*, foot amputation due to infection after a gunshot wound, foot mutilation after a snake bite, and severe burning of bilateral hands during early childhood. None of these persons received orthopedic surgery prior to study participation.

## 3.1. General beliefs

Table 2 contains the results of the cultural beliefs expressed by all respondents irrespective of type of disability. Half of the respondents thought that it was hard to make friends, and 81% thought that being accompanied by someone else was always needed. Sixty-five percent considered disability to be contagious, and 52% believed that disability was caused by spirits, known as *irans*. A minority of 26% considered their disability to be a punishment for sin (that is, sins conducted by family, parents, or the community), and 74% thought that individuals with a disability could be as successful as nondisabled persons. More than half considered disability to be a blood disorder. As one of the respondents argued: “after an epileptic attack the entire body is weak, so it should be a blood disorder”.

## 3.2. Differences related to religious background

The comparison of respondents according to individuals' religious backgrounds is also presented in Table 2. We found significant differences between religious backgrounds regarding the belief that disability was a punishment for sin. Eighty percent of traditional believers thought that this was true, in contrast to the 8% among Christians and the 26% among Muslims. Muslim respondents mentioned ‘*Allah Willing*’ and not sin as the cause of disability.

Respondents with a Muslim background were significantly more positive about people with a disability to be as successful in society as others (93%), as compared to Christians (67%) and traditional believers (40%). Equality between the disabled and the nondisabled was confirmed among Muslims (57%) and respondents that adhered to traditional religions (60%). This was much lower among Christian respondents (17%). Of the Christian respondents, 92% thought that people with a disability should always be accompanied by someone else. This percentage was lower among Muslims (79%) and traditional believers (60%).

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