



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%).

Table 2
Outcome and odds ratios (OR) of beliefs in people with epilepsy or physical impairment. N: number of respondents that answered yes. CI: confidence interval.

Beliefs expressed by participants	Total N (%)	Traditional believers N (%)	Christians N (%)	Muslims N (%)	Muslim vs traditional believers OR (95% CI), P-value	Christians vs traditional believers OR (95% CI), P-value	Group with physical impairment N (%)	Group with epilepsy N (%)	Group with epilepsy vs group with physical impairment OR (95% CI), P-value
Is it hard to make friends having epilepsy/physical impairment? [yes]	15 (48.4)	3 (60)	4 (33.3)	8 (57.1)	0.89 (0.09–7.14), 0.91	0.33 (0.03–2.81), 0.32	9 (56.2)	6 (40)	0.52 (0.12–2.14), 0.37
Should a person with epilepsy/physical impairment always be with someone? [yes]	25 (80.6)	3 (60)	11 (91.7)	11 (78.6)	2.44 (0.24–23.4), 0.43	7.33 (0.53–195.32), 0.15	14 (87.5)	11 (73.3)	0.39 (0.05–2.4), 0.33
Are people with epilepsy/physical impairment equal to others? [yes]	13 (41.9)	3 (60)	2 (16.7)	8 (57.1)	0.89 (0.09–7.14), 0.91	0.13 (0.01–1.28), 0.09	7 (43.8)	6 (40)	0.86 (0.2–3.61), 0.83
Does the religion you adhere to consider people with epilepsy/physical impairment equal to others? [yes]	14 (45.2)	5 (100)	2 (16.7)	7 (50)	0 (not estimable), 0.99	0 (not estimable), 0.99	5 (31.2)	9 (60)	3.3 (0.78–15.54), 0.11
Is epilepsy/physical impairment a contagious disease? [yes]	20 (64.5)	4 (80)	9 (75)	7 (50)	0.25 (0.01–2.25), 0.26	0.75 (0.03–8.3), 0.83	9 (56.2)	11 (73.3)	2.14 (0.48–10.48), 0.32
Is epilepsy/physical impairment caused by spirits? [yes]	16 (51.6)	3 (60)	6 (50)	7 (50)	0.67 (0.07–5.29), 0.7	0.67 (0.07–5.53), 0.71	7 (43.8)	9 (60)	1.93 (0.47–8.42), 0.37
Is epilepsy/physical impairment a punishment for sins? [yes]	8 (25.8)	4 (80)	1 (8.3)	3 (21.4)	0.07 (0–0.67), 0.04	0.02 (0–0.31), 0.01	4 (25)	4 (26.7)	1.09 (0.21–5.67), 0.92
Is epilepsy/physical impairment a blood disorder? [yes]	16 (51.6)	4 (80)	7 (58.3)	5 (35.7)	0.14 (0.01–1.26), 0.11	0.35 (0.02–3.36), 0.41	7 (43.8)	9 (60)	1.93 (0.47–8.42), 0.37
Could people with epilepsy/physical impairment be as successful as others? [yes]	23 (74.2)	2 (40)	8 (66.7)	13 (92.9)	19.5 (1.64–538), 0.03	3 (0.36–31.12), 0.32	11 (68.8)	12 (80)	1.82 (0.36–10.62), 0.48
Should the funeral of people with epilepsy/physical impairment be similar to other funerals? [yes]	25 (80.6)	4 (80)	10 (83.3)	11 (78.6)	0.92 (0.04–10), 0.95	1.25 (0.05–17.24), 0.87	15 (93.8)	10 (66.7)	0.13 (0.01–0.99), 0.08

3.3. Epilepsy versus physical impairment

We found no significant differences between the group with epilepsy and the group with physical impairment. However, two-thirds of PWE thought that funerals of PWE were different from those of persons without disability. The belief among Guineans was the fear of an *iran* returning to a new family member if a possessed person is buried with visible grief, and the body is wrapped in clothes. Respondents from the group with physical impairment thought that no distinction should be made in ceremonial procedures during a funeral (for example, mourning, severe crying, and monodies on the first day after death, wrapping of the corpse in beautiful robes, and inviting many people to attend). Sixty percent in the group with epilepsy thought that their religion did not discriminate between disabled and healthy individuals. This percentage was lower in the physical impairment group (31%).

4. Discussion

In this study, we identified cultural beliefs among people with disability in Guinea-Bissau and related those to the religious background and type of disability. We found poor knowledge of and negative attitudes towards disability among persons with a disability. Cultural beliefs were significantly shaped by religious background, whereas differences between epilepsy and physical impairment were more subtle. The knowledge was poor as half of the respondents considered a physical impairment or epilepsy to be a blood disorder or caused by spirits; two-thirds of the respondents thought of their condition as being contagious, and three-fourths associated epilepsy or physical impairment with supernatural punishment.

The negative attitudes we found among people with a disability are comparable to findings reported from Tanzanian individuals with a disability [20]. Individuals with epilepsy and physical impairments face negative attitudes because of their inability to fully participate in daily activities such as attending school, finding a job, or raising a family. The heavy reliance of the community in Guinea-Bissau on agriculture and fishing, which involves all healthy family members, might partly explain these attitudes in our study. Not being able to contribute to the family earnings in a low-income country will influence self-esteem, independence, and respect and may also lead to discrimination.

We found individuals with a disability that had a Muslim background to be more positive about their disability. Muslims believe that everything is 'written', and so, whatever it is that one wishes to do will only occur if it is within God's plan. This may explain our data. Our results also corroborate findings from a study conducted among nondisabled students in the Caribbean that found a relatively low perception of stigma among Muslims as compared to Hindu students [21].

In addition to religious background, we compared individuals with a disability according to the type of disability: epilepsy or a physical impairment. We are not aware of previous studies with similar comparisons, but we believe that this is important information to increase the effectiveness of inclusive community interventions in stigma reduction and reintegration of people with a disability in society. Mapping of familiarity with, understanding of, and attitudes towards people with a disability in sub-Saharan Africa has mainly focused on epilepsy [5]. This may give the incorrect impression that disability-related stigma and social exclusion are restricted to, or more severe in, people with epilepsy as compared to individuals with, for instance, physical impairments. Indeed, people with physical impairments who fully participate in daily activities are likely to be considered 'normal' [20,22,23], but this

is equally true for PWE who have been free of epilepsy for a period of time or have fewer seizures. A strong association has been found between the negative effects of stigma and a high seizure frequency [24,25]. Nonetheless, other studies found that a sense of stigma may persist even after excellent seizure control, as shown in studies across Europe (reviewed in [26]). Whether this is true for Guinea-Bissau is unknown. However, the similarities found in our study between the beliefs of PWE and individuals with physical impairment indicate that the ability to participate in common social, educational, and economic community activities may be more important for the person with a disability in terms of acceptance and perceived stigma than the specific type of disability.

Our study has limitations. The CBR program started in 2011; as a result, the study sample is small, and our results should, therefore, ideally be verified in larger populations. Selection bias might also be present. People with disabilities that are hidden by their families and hence remain unknown to community workers could not be included. In addition, we only compared epilepsy with physical impairment. Hence, there is caution in generalizing our results to other forms of disability. Additional research is needed to address similarities and differences in cultural beliefs in other groups, such as persons with blindness or deafness. Future work, using a much larger sample size, might also look into the additional effects of burns and other seizure-related injuries on attitudes towards PWE. We did not include PWE with burns in this study. In some African societies, epilepsy is referred to as the 'burn disease' because most burns in females are caused by seizures while cooking over open fire [27]. Facial scars and burn scar contractures are likely to increase negative attitudes in the community and impede social inclusion of affected individuals.

Despite these limitations, our results are useful in a first step towards understanding what people with disabilities believe and how these beliefs are colored by religious background.

In conclusion, people in Guinea-Bissau who live with disability face many barriers to full participation in the community. To be able to support them to achieve their maximum potential, it is most of all important to understand their personal beliefs. A better mapping of these beliefs—taking the local culture, tradition, and religion into account—may render CBR programs more effective, particularly those with a focus on disability-inclusive development.

Conflict of interest

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

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References

- [1] Watts TE. Disabled in developing countries. *Lancet* 1999;354:1477.
- [2] Bartolini E, Bell GS, Sander JW. Multicultural challenges in epilepsy. *Epilepsy Behav* 2011;20:428–34.
- [3] de Boer HM. Epilepsy stigma: moving from a global problem to global solutions. *Seizure* 2010;19:630–6.
- [4] Gona JK, Mung'ala-Odera V, Newton CR, Hartley S. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child Care Health Dev* 2010;37:175–83.
- [5] Lua PL, Neni SW. Awareness, knowledge and attitudes towards epilepsy: a review of a decade's research between 2000 and 2010. *Afr J Neurol Sci* 2012;30.
- [6] Atadzhanov M, Chomba E, Haworth A, Mbewe E, Birbeck GL. Knowledge, attitudes, behaviors, and practices regarding epilepsy among Zambian clerics. *Epilepsy Behav* 2006;9:83–8.
- [7] Ojinnaka NC. Teachers' perception of epilepsy in Nigeria: a community-based study. *Seizure* 2002;11:386–91.
- [8] Ndour D, Ndiaye M, Diop AG, Niang C, Sarr MM, Ndiaye IP. A survey of school teachers' knowledge and behaviour about epilepsy, in a developing country such as Senegal. *Rev Neurol (Paris)* 2004;160:338–41.
- [9] Sanya EO, Salami TA, Goodman OO, Buhari OI, Araoye MO. Perception and attitude to epilepsy among teachers in primary, secondary and tertiary educational institutions in middle belt Nigeria. *Trop Doct* 2005;35:153–6.
- [10] Mbewe E, Haworth A, Atadzhanov M, Chomba E, Birbeck GL. Epilepsy-related knowledge, attitudes, and practices among Zambian police officers. *Epilepsy Behav* 2007;10:456–62.
- [11] Chomba EN, Haworth A, Atadzhanov M, Mbewe E, Birbeck GL. Zambian health care workers' knowledge, attitudes, beliefs, and practices regarding epilepsy. *Epilepsy Behav* 2007;10:111–9.
- [12] Vivas AP, Gelaye B, Aboset N, Kumie A, Berhane Y, Williams MA. Knowledge, attitudes and practices (KAP) of hygiene among school children in Angolela, Ethiopia. *J Prev Med Hyg* 2012;51:73–9.
- [13] Njamnshi AK, Tabah EN, Bissek AC, Yepnjio FN, Kuete C, Angwafor SA, et al. Knowledge, attitudes and practice with respect to epilepsy among secondary school students in the Kumbo West Health District – North West Region – Cameroon. *Epilepsy Behav* 2010;18:247–53.
- [14] Matuja WB, Rwiza HT. Knowledge, attitude and practice (KAP) towards epilepsy in secondary school students in Tanzania. *Cent Afr J Med* 1994;40:13–8.
- [15] Klugman J. Human development report 2011. New York: United Nations Development Programme; 2011.
- [16] Mitra S, Posarac A, Vick B. Disability and poverty in developing countries: a snapshot from the world health survey. World Bank social protection working paper; 2011.
- [17] Romeiras MM, Duarte MC, Indjai B, Catarino L. Medicinal plants used to treat neurological disorders in West Africa: a case study with Guinea-Bissau flora. *Am J Plant Sci* 2012;3:1028–36.
- [18] Kassah AK. Community-based rehabilitation and stigma management by physically disabled people in Ghana. *Disabil Rehabil* 1998;20:66–73.
- [19] Mitchell RA, Zhou D, Lu Y, Watts G. Community-based rehabilitation: does it change community attitudes towards people with disability? *Disabil Rehabil* 1993;15:179–83.
- [20] Stone-MacDonald A. Cultural beliefs about disability in practice: experiences at a special school in Tanzania. *Int J Disabil Dev Educ* 2012;59:393–407.
- [21] Youssef FF, Dial S, Jaggermath N, Jagdeo CL, Pascall A, Ramessar L, et al. Knowledge of, attitudes toward, and perceptions of epilepsy among college students in Trinidad and Tobago. *Epilepsy Behav* 2009;15:160–5.
- [22] Wormnas S, Olsen M. Mothers' hearts speaking: education enlightens, empowers and protects girls with disabilities. *Int J Spec Educ* 2009;24:64–74.
- [23] Kaplan D. The definition of disability: perspective of the disability community. *J Health Care L Pol'y* 2000;3:352.
- [24] Guekht AB, Mitrokhina TV, Lebedeva AV, Dzugaeva FK, Milchakova LE, Lokshina OB, et al. Factors influencing on quality of life in people with epilepsy. *Seizure* 2007;16:128–33.
- [25] Jacoby A, Snape D, Baker GA. Epilepsy and social identity: the stigma of a chronic neurological disorder. *Lancet Neurol* 2005;4:171–8.
- [26] Baker GA, Brooks J, Buck D, Jacoby A. The stigma of epilepsy: a European perspective. *Epilepsia* 2000;41:98–104.
- [27] Baker GA. The psychosocial burden of epilepsy. *Epilepsia* 2002;43(Suppl. 6):26–30.