

Published in final edited form as:

Epilepsy Behav. 2010 November ; 19(3): 414–418. doi:10.1016/j.yebeh.2010.08.017.

Epilepsy-Associated Stigma in Zambia: What factors predict greater felt stigma in a highly stigmatized population?

Masharip Atadzhanov, Alan Haworth, Elwyn N. Chomba, Edward K. Mbewe, and Gretchen Lano Birbeck

Department of Medicine, University of Zambia, Lusaka, Zambia; Department of Psychiatry, University of Zambia, Lusaka, Zambia (retired); Department of Paediatrics and Child Health, University of Zambia, Lusaka, Zambia; Chainama Hills College Hospital, Lusaka, Zambia; Chikankata Hospital, Epilepsy Care Team, Mazabuka, Zambia and International Neurologic & Psychiatric Epidemiology Program, Michigan State University, East Lansing, MI, USA

Abstract

Epilepsy-associated stigma in Africa has been largely described in terms of enacted stigma or discrimination. We conducted a study of 169 adults with epilepsy attending epilepsy clinics in Zambia's Lusaka or Southern province using a 3-item instrument (maximum score 3). Potential determinants of felt stigma including age, gender, education, wealth, disclosure status (meaning whether or how their community members knew of their condition), seizure type (generalized vs. partial), seizure frequency, the presence of visible epilepsy-associated stigmata, personal contagion beliefs and community contagion beliefs were also assessed. The median stigma score was 2.5, suggesting some ceiling effect in the instrument. People with epilepsy who believed their condition to be contagious, who thought their community believed epilepsy to be contagious and whose condition had been revealed to their community against their wishes reported more felt stigma. Community and clinic-based educational campaigns to dispel contagion beliefs are needed.

Keywords

contagion beliefs; disclosure; stigmata; felt stigma; epilepsy

Introduction

The concept of health-related stigma has been conflated somewhat since Goffman's original descriptions.(1) According to the modern conceptualization, stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold.(2) This conceptualization suggests that stigma is likely to be a key determinant of many of the life chances from psychological well-being to employment, housing, and life/survival itself. Epilepsy has long been

© 2010 Elsevier Inc. All rights reserved.

Corresponding Author: Gretchen L. Birbeck, #324 West Fee Hall, East Lansing, MI 48824, USA, Tele +1-517-884-0277, Fax +1-517-884-0275, Birbeck@msu.edu.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

recognized as a condition generally associated with a significant burden of health-related stigma.

Stigma associated with epilepsy continues to be significant in both developed and developing countries, and stigma is a well-researched concept in the literature on psychosocial aspects of epilepsy. (3) Scambler and Hopkins(4) proposed that stigma has two forms for people with epilepsy (PWE): enacted and felt. Enacted stigma refers to discriminative situations against a person with epilepsy. (5) Felt stigma may result from enacted stigma, but stigma may be “felt” or perceived even if it has not been acted upon. The fear of being discriminated against or stigmatized because of one’s condition can be very troubling even if the actual stigmatizing event feared does not occur. (6) Felt stigma can cause individuals with epilepsy to substantially limit their life opportunities and trajectories.

The stigma literature shows the complexity of the stigma phenomenon and the need for further research. (7,8) It was argued that some conditions of stigma are culturally dependent, others appear to be universal(9), and the factors associated with stigma are likely multifaceted. A cross-cultural study of epilepsy-associated stigma in ten European countries found that more than half of all respondents did not feel stigmatized at all by their epilepsy and only 17% reported feeling very stigmatized by it.(10) There were significant differences between countries reporting feelings of stigma. Respondents in the Netherlands (27%), and Spain (31%) were significantly less likely to feel stigmatized than were those in Poland (56%) and France (62%). Epilepsy-associated stigma remains prevalent in many Asian countries with significant differences between countries.(11) For example, in South Korea(12), Iran, Hong-Kong(13) and Thailand (MA43) respondents feel more stigma than respondents in Pakistan(14,15), China and Vietnam. (16) Although people with epilepsy (PWE) in Pakistan do not appear to be highly stigmatized, people of Pakistani origin living in the north of England report experiencing significant stigma and discrimination.(17) Epilepsy-associated stigma remains high in India (18,19)Laos (20) and Arab countries. (21–23)

Nowhere is epilepsy-associated stigma more disabling than in sub-Saharan Africa (SSA). (24) Possibly due to contagion fears, stigma in SSA extends beyond the individual to family members and other close associates. (25–29). The person with epilepsy is socioeconomically disadvantaged due to discrimination in employment and educational opportunities, the risk of abandonment by spouse and/or family and increased vulnerability to rape and physical abuse. (30) Review of the articles from Asia, Europe, and the US show that the most consistent predictor of stigma is seizure frequency; people with high seizure frequency being more likely have high level of stigma. (11,16,31,32) To date most studies of epilepsy-associated stigma in Africa have focused upon enacted stigma (33) and few quantitative studies to identify determinants of epilepsy-associated stigma in SSA have been published. (29,34)

Remarkable achievements in understanding the etiology, pathogenesis, genetics and treatment of epilepsy have resulted in excellent control of seizures in many people with epilepsy (PWE). However, the stigma surrounding epilepsy continues to be associated with many negative public attitudes evident in numerous knowledge, attitude and practice surveys. (27,35–37) PWE continue to suffer from enacted or felt stigma that is presumably based on myths, misconceptions and misunderstandings that have persisted for thousands of years in all cultures. (6,38) Moreover, cross-cultural comparisons revealed significant differences between cultures, continents, countries, and even between regions of the same country. (10,11,16,39) A multivariate analysis in Europe identified significant contributors to stigma including, age of onset, country and region of origin, feelings about life, and

injuries associated with epilepsy. (10) It has been proposed that stigmatization is the result of the continuous interaction between socio-cultural and biological processes in conditions of chronic illness. (40) Studies in poor-resource countries (18–20,40,41), including Zambia (30), suggest a greater burden of epilepsy associated stigma in developing countries vs. developed countries. (30,42)

Understanding and reducing epilepsy-associated stigma is one of the stated aims of the World Health Organization's Global Campaign Against Epilepsy (GCAE) "Out of the Shadows" initiative. (43) The impact of epilepsy-related stigma on both disease burden and quality of life is of great significance in resource-poor countries. In these countries, epilepsy represents a major public health problem. (2,3,44,45) In sub-Saharan Africa (SSA) epilepsy rates remains very high and the combination of poverty, limited medical care, and traditional beliefs coalesce to severely limit the lives of PWE. In addition to clinical interventions, stigma-reduction interventions are important for improving the lives of PWE.

Stigma is thought to be distributed along power differentials where people with less power (the poor, marginalized, and vulnerable) are likely to be more stigmatized when exposed to the same stigmatizing disease state relative to a more powerful person with the same disorder would experience. (46) The potential burden of health-related stigma may lead people with stigmatizing condition, such as epilepsy, leprosy or HIV, to conceal their condition. Failure to disclose one's potentially stigmatizing medical problems has implications for an individual's health if they fail to seek medical care because of efforts to hide their condition. For contagious conditions, there are public health risks implicit if care seeking is delayed. We know little about how to change negative attitudes and experiences about epilepsy in an effective and sustainable fashion. (3) Developing stigma-reducing interventions requires a better understanding the fundamental causes of stigma. Any successful interventions will likely be multifaceted and multilevel. (47,48)

To better understand determinants of epilepsy-associated felt stigma in a region where epilepsy is highly stigmatized, we undertook a study aimed at identifying underlying determinants of greater felt stigma in Zambia.

Methods

The study population consisted of PWE who were part of a case-control study comparing the social and economic impact of epilepsy to other non-stigmatizing chronic health conditions. (30)

Seven outpatient sites providing epilepsy care were included in this study—five urban, one rural, and one mixed site. The urban sites included the outpatient specialty clinic at the University of Zambia's University Teaching Hospital in Lusaka and four free-standing clinics in Lusaka associated with Chainama Hills Hospital. Monze Mission Hospital, located on the main tarmac road between Lusaka and Livingstone, serves a mixed peri-urban and rural population in its outpatient department. Chikankata Health Service, located 31 km off the tarmac road 120 km south of Lusaka, operates a busy outpatient department serving a rural population of subsistence farmers. Each site provides care for people with epilepsy as well as for those with a range of medical problems common in the region.

Enrolment and interviews were undertaken between Sept 1, and Dec 31, 2005. Research staff consisted of local healthcare workers fluent in both English and the applicable local languages (Bemba, Tonga, or Nyanja). All research staff received a week of intensive training together as a group to decrease inter-site variability. Potential cases were patients at least 18 years of age who were receiving care for an established diagnosis of epilepsy and who were able to answer questions without assistance from a proxy respondent. At each site,

clinical staff registering patients for outpatient visits as well as healthcare workers in the clinic alerted potential participants about the study, their possible eligibility, and where the research office could be found. Potential study participants who presented to the research staff were given further details about participation and eligibility was assessed. Eligible potential subjects were then engaged in a discussion regarding informed consent.

Consenting subjects were interviewed in a private setting. Answers to interview questions were recorded on paper copies of the instrument along with study identification numbers. Names were not recorded on the instrument, but clinic staff made note in their outpatient file of who had already been referred to the study team to avoid duplicate interviews. Interviewers obtained demographic data (age, gender, marital status, household wealth) as well as information regarding the nature of the person's epilepsy (seizure type, seizure frequency, history of seizure-related injury), their contagion beliefs as well as their assessment of contagion beliefs within the community, and their disclosure status within the community, in terms of whether or not people in their community are aware of their epilepsy and if so whether disclosure was voluntary, or forced when they either had a public seizure or someone who knew about their epilepsy shared this information with others. Felt stigma was assessed via a previously validated three-item stigma scale comprised of dichotomous questions in which a positive response is indicative of felt or perceived stigma with an overall possible score ranging from 0 (no felt stigma) to 3 (maximally felt stigma). (49) Interviewers were also asked to report, rather than ask the respondent, whether or not the respondent had epilepsy-associated stigmata meaning scars consistent with/associated with seizure related injuries. In Zambia, these are visible burn scars and or facial scarring consistent with a facial injury.

Completed questionnaires were copied and copies stored in the central study office at Chikankata. Original hardcopies were used to double-enter data into Microsoft Access before importation into EPI INFO 3.2.2 for analysis. Descriptive data for demographic and clinical characteristics were reviewed as well as information on contagion beliefs, disclosure status, and the findings from the administration of the stigma scale. To examine whether demographic factors, clinical features, or social exposures including disclosure status and contagion beliefs predicted felt stigma, we treated the overall stigma score as a continuous variable and used the student's t test, or the Kruskal-Wallis test. Based upon suggestions from local primary healthcare workers and patient advocacy groups after presentation of the preliminary data, we conducted a post hoc analysis to assess the relationship between disclosure status and wealth using the Kruskal-Wallis test.

This study was approved by the University of Zambia's Research Ethics Committee and Michigan State University's Committee for Research involving Human Subjects. Consent was sought in the potential participants' preferred language (English, Tonga, Bemba, or Nyanja). The written consent form was provided and was read and discussed orally. Signed consent forms could include a formal signature, an "X", or a thumbprint based upon the study subject's preference.

Results

Among 176 potential study subjects, 169 (96.0%) agreed to participate. The demographic and clinical characteristics of participants are outlined in Table 1. The mean age of respondents was 35.5 (range, 16–77 years), and almost half of them (50.3%) were male. More than 94% patients experience generalized tonic-clonic (GTC) seizures. Most of them (81%) had 1–3 seizures per months. About 40% of respondents reported a history of a significant seizure-related injury.

Characteristics associated with felt stigma are summarized in Table 2. Stigma score ranged from 0 to 3 (mean 1.8, median 2.5, mode 3, SD 1.3). Table 3 details the findings from the assessment to identify potential determinants of stigma. Higher stigma scores were associated with community disclosure, being greatest for those who had forced disclosure either through a public seizure or someone else revealing their condition to the community. People who believed their condition to be contagious or who reported contagion beliefs from within their community also had higher felt stigma. Stigma scores were not associated with age, gender, stigmata, wealth, seizure-type or seizure frequency. In our *post hoc* analysis, of the relationship between disclosure status and wealth, we found that the ability to choose to conceal one's epilepsy was significantly associated with one's wealth (mean wealth for voluntary disclosure \$843; forced \$770 and none \$2,738; $p=0.04$).

Discussion

Among this study of a large population of people with epilepsy from both rural and urban areas, disease and stigma burden was high. Voluntary disclosure of one's status as a person with epilepsy was unusual in our study population. This may be very understandable since people who have been able to conceal their condition experienced less felt stigma. Felt stigma was less for those who were able to conceal their condition from their community and was greater for PWE who believed their condition to be contagious and/or who resided in communities where contagion beliefs were common. Our *post hoc* analysis of the relationship between wealth and disclosure status suggests that those with greater wealth may have domestic situations offering a level of privacy not routinely available to most (*e.g.* larger homes so less time spent out in the open, etc.)

Some limitations of this work deserve mention. All of the PWE surveyed were identified through the clinic where they receive care and as such all of them were on treatment. Since the epilepsy treatment gap is >80% in Zambia(50), this is not a representative population. PWE off treatment may have a greater seizure frequency and severity, though milder cases of epilepsy may also be less likely to present for care. Previous studies have indicated PWE in Zambia who are not receiving treatment have a greater risk of significant injury. (51) Our information on community contagion beliefs were obtained through the PWE and represent their perspective of what the community belief is. A more rigorous but methodologically difficult endeavor would be to measure contagion beliefs with each of the many communities. We only assessed felt stigma in this work and our measure was a limited 3-item tool. More detailed extensive stigma measurement tools have been recently developed and might offer better insights into the phenomena.(39)

Traditional beliefs regarding epilepsy in Zambia are often deeply flawed and incorrect (52–57), but in this quantitative study, the important role that contagion beliefs play in felt stigma in this population is notable. Other characteristics we hypothesized might be associated with less felt stigma, such as wealth and the absence of epilepsy stigmata, were not significant factors in this study. Contagion fears have been reported from other regions including Tanzania, Nigeria and even Spanish speaking adults in the US (27,52,58–63), but this is the first quantitative study to delineate the strong relationship between felt stigma and contagion beliefs.

Based upon this study, stigma reduction programs should include major efforts to dispel contagion beliefs among PWE as well as the greater community. If only a single message or “sound bite” can be conveyed, addressing contagion beliefs and debunking these may be the most effective single message.

Acknowledgments

The project described was supported by Award Numbers R21NS48060 and 1R01NS061693 from the National Institute of Neurological Disorders And Stroke. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Neurological Disorders and Stroke or the National Institutes of Health.

References

1. Goffman, E. Notes on the management of spoiled identity. Penguin, Harmondsworth: 1963.
2. Link, B.; Phelan, J. Stigma and Global Health: Developing a REsearch Agenda; 2001. Bethesda, Maryland: 2001. On Stigma and its public health implications.
3. Jacoby A. Epilepsy and Stigma: An Update and Critical Review. *Current Neurol Neurosci Rep* 2008;8:339–344.
4. Scambler G, Hopkins A. Being epileptic: coming to terms with stigma. *Social Health Illness* 1986;8:26–43.
5. Jacoby A, Gorry J, Gamble C, Baker GA. Public knowledge, private grief: a study of public attitudes to epilepsy in the United Kingdom and implications for stigma. *Epilepsia* 2004 Nov; 45(11):1405–1415. [PubMed: 15509242]
6. Bandstra NF, Camfield CS, Camfield PR. Stigma of epilepsy. *Can J Neurol Sci* 2008 Sep;35(4): 436–440. [PubMed: 18973059]
7. Scambler G. Reframing Stigma: Felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory and Health* 2004;2:29–46.
8. Kilink S, Campbell C. "It should be something that's evil, it should be talked about": The phenomenological approach to epilepsy and stigma. *Seizure* 2009;18:665–671. [PubMed: 19819737]
9. Jones, E.; Farina, A.; Hastorf, A. *Social Stigma: THE Psychology of Marked Relationships*. New York: Freeman; 1984.
10. Baker G, Brooks J, Buck D, Jacoby A. The Stigma of Epilepsy: A European Perspective. *Epilepsia* 1999;41(1):98–104. [PubMed: 10643931]
11. Lim Y, Chan S, Ko T. Stigma and health-related quality of life in Asian adults with epilepsy. *Epilepsy Research* 2009;87:107–119. [PubMed: 19782536]
12. Lee SA, Yoo HJ, Lee BI. Factors contributing to the stigma of epilepsy. *Seizure* 2005 Apr;14(3): 157–163. [PubMed: 15797349]
13. Wong V, Chung B, Wong R. Pilot study of public awareness, attitudes and understanding toward epilepsy in Hong Kong. *Neurol J Southeast Asia* 2004;9:21–27.
14. Aziz H, Akhtar SW, Hasan KZ. A population- based epidemiologic study. Epilepsy in Pakistan: stigma and psychosocial problems. *Epilepsia* 1997;38(10):1069–1073. [PubMed: 9579952]
15. Shafiq M, Tanwir M, Tariq A, Kasi PM, Zafar M, Saleem A, et al. Epilepsy: Public knowledge and attitude in a slum area of Karachi, Pakistan. *Seizure*. 2007 Mar 20;
16. Jacoby A, Wang W, Vu TD, Wu J, Snape D, Aydemir N, et al. Meanings of epilepsy in its sociocultural context and implications for stigma: findings from ethnographic studies in local communities in China and Vietnam. *Epilepsy Behav* 2008 Feb;12(2):286–297. [PubMed: 18032116]
17. Rhodes PJ, Small NA, Ismail H, Wright JP. 'What really annoys me is people take it like it's a disability', epilepsy, disability and identity among people of Pakistani origin living in the UK. *Ethn Health* 2008 Jan;13(1):1–21. [PubMed: 18066735]
18. Santosh D, Kumar TS, Sarma PS, Radhakrishnan K. Women with onset of epilepsy prior to marriage: disclose or conceal? *Epilepsia* 2007 May;48(5):1007–1010. [PubMed: 17386055]
19. Radhakrishnan K, Pandian JD, Santhoshkumar T, Thomas SV, Deetha TD, Sarma PS, et al. Prevalence, knowledge, attitude, and practice of epilepsy in Kerala, South India. *Epilepsia* 2000 Aug;41(8):1027–1035. [PubMed: 10961631]

20. Tran DS, Odermatt P, Singphuangphet S, Druet-Cabanac M, Preux PM, Strobel M, et al. Epilepsy in Laos: knowledge, attitudes, and practices in the community. *Epilepsy Behav* 2007 Jun;10(4): 565–570. [PubMed: 17446140]
21. Al-Adawi S, Al-Ismaily S, Martin R, Al-Naamani A, Al-Riyami K, Al-Maskari M, et al. Psychosocial aspects of epilepsy in Oman: attitude of health personnel. *Epilepsia* 2001 Nov; 42(11):1476–1481. [PubMed: 11879353]
22. Daoud A, Al-Safi S, Ootom S, Wahba L, Alkofahi A. Public knowledge and attitudes towards epilepsy in Jordan. *Seizure* 2007 Sep;16(6):521–526. [PubMed: 17543545]
23. Obeid T. Stigma. An aspect of epilepsy not to be ignored. *Saudi Med J* 2008 Apr;29(4):489–497. [PubMed: 18382786]
24. Baskind R, Birbeck GL. Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease. *Epilepsy Behav* 2005 Aug;7(1):68–73. [PubMed: 15978874]
25. Jilek WG, Jilek-Aall LM. The problem of epilepsy in a rural Tanzanian tribe. *Afr J Med Sci* 1970 Jul;1(3):305–307. [PubMed: 5521687]
26. Giel R. The epileptic outcast. *East Afr Med J* 1968 Jan;45(1):27–31. [PubMed: 5649590]
27. Rwiza HT, Matuja WB, Kilonzo GP, Haule J, Mbena P, Mwang'ombola R, et al. Knowledge, attitude, and practice toward epilepsy among rural Tanzanian residents. *Epilepsia* 1993;34(6): 1017–1023. [PubMed: 8243350]
28. Birbeck GL. Barriers to care for patients with neurologic disease in rural Zambia. *Arch Neurol* 2000 Mar;57(3):414–417. [PubMed: 10714673]
29. Allotey P, Reidpath D. Epilepsy, culture, identity and well-being: a study of the social, cultural and environmental context of epilepsy in Cameroon. *J Health Psychol* 2007 May;12(3):431–443. [PubMed: 17439994]
30. Birbeck G, Chomba E, Atadzhanov M, Mbewe E, Haworth A. The social and economic impact of epilepsy in Zambia: a cross-sectional study. *Lancet Neurol* 2007 Jan;6(1):39–44. [PubMed: 17166800]
31. Baker GA. People with epilepsy: what do they know and understand, and how does this contribute to their perceived level of stigma? *Epilepsy Behav* 2002 Dec;3(6S2):26–32. [PubMed: 12609303]
32. Smith G, Ferguson PL, Saunders LL, Wagner JL, Wannamaker BB, Selassie AW. Psychosocial factors associated with stigma in adults with epilepsy. *Epilepsy Behav* 2009 Nov;16(3):484–490. [PubMed: 19782005]
33. Rafael F, Houinato D, Nubukpo P, Dubreuil CM, Tran DS, Odermatt P, et al. Sociocultural and psychological features of perceived stigma reported by people with epilepsy in Benin. *Epilepsia*. Feb 3;
34. Adewuya AO, Oseni SB, Okeniyi JA. School performance of Nigerian adolescents with epilepsy. *Epilepsia* 2006 Feb;47(2):415–420. [PubMed: 16499769]
35. Fong CY, Hung A. Public awareness, attitude, and understanding of epilepsy in Hong Kong Special Administrative Region, China. *Epilepsia* 2002;43(3):311–316. [PubMed: 11906517]
36. Nyame PK, Biritwum RB. Epilepsy: knowledge, attitude and practice in literate urban population, Accra, Ghana. *West Afr J Med* 1997;16(3):139–145. [PubMed: 9329281]
37. Matuja WB, Rwiza HT. Knowledge, attitude and practice (KAP) towards epilepsy in secondary school students in Tanzania. *Cent Afr J Med* 1994;40(1):13–18. [PubMed: 8082145]
38. Jacoby A, Austin JK. Social stigma for adults and children with epilepsy. *Epilepsia* 2007;48 Suppl 9:6–9. [PubMed: 18047591]
39. Fernandes PT, Salgado PC, Noronha AL, Sander JW, Li LM. Stigma Scale of Epilepsy: validation process. *Arq Neuropsiquiatr* 2007 Jun;65 Suppl 1:35–42. [PubMed: 17581666]
40. Neuberg, S.; Smith, S.; Asher, T. Why people stigmatize: Toward a biocultural framework. In: Heatherton, T.; Kleck, R.; Hebl, H.; Hull, J., editors. *The Social Psychology of Stigma*. New York: The Guilford Press; 2000.
41. Kleinman A, Wang WZ, Li SC, Cheng XM, Dai XY, Li KT, et al. The social course of epilepsy: chronic illness as social experience in interior China. *Soc Sci Med* 1995 May;40(10):1319–1330. [PubMed: 7638642]
42. Morrell MJ. Stigma and epilepsy. *Epilepsy Behav* 2002 Dec;3(6S2):21–25. [PubMed: 12609302]

43. de Boer HM, Engel J Jr, Prilipko LL. "Out of the shadows": a partnership that brings progress! *Epilepsia* 2005;46 Suppl 1:61–62. [PubMed: 15816985]
44. Bruce JC, Imperato PJ, Wilson JN. Marrying modern health practices and technology with traditional practices: issues for the African continent Western and traditional medicine in Africa: a century of encounter Iatrogenic gangrene in the Third World. *Int Nurs Rev* 2002;49(3):161–167. [PubMed: 12243593]
45. WHO. Geneva, Switzerland: WHO Press; 2006. *Neurological Disorders: Public Health Challenges*.
46. Corrigan PW. Target-specific stigma change: a strategy for impacting mental illness stigma. *Psychiatr Rehabil J* 2004 Fall;28(2):113–121. [PubMed: 15605746]
47. Birbeck G. Interventions to reduce epilepsy-associated stigma. *Psychol Health Med* 2006 Aug; 11(3):364–366. [PubMed: 17130072]
48. Link BG, Struening EL, Neese-Todd S, Asmussen S, Phelan JC. Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatr Serv* 2001;52(12):1621–1626. [PubMed: 11726753]
49. Jacoby A, Baker G, Smith D, Dewey M, Chadwick D. Measuring the impact of epilepsy: the development of a novel scale. *Epilepsy Res* 1993;16(1):83–88. [PubMed: 8243442]
50. Birbeck GL, Kalichi EM. Epilepsy prevalence in rural Zambia: a door-to-door survey. *Trop Med Int Health* 2004 Jan;9(1):92–95. [PubMed: 14728612]
51. Birbeck GL. Seizures in rural Zambia. *Epilepsia* 2000;41(3):277–281. [PubMed: 10714398]
52. Alikor EA, Essien AA. Childhood epilepsy: knowledge and attitude of primary school teachers in Port Harcourt, Nigeria. *Niger J Med* 2005 Jul–Sep;14(3):299–303. [PubMed: 16350702]
53. Atadzhanov M, Chomba E, Haworth A, Mbewe E, Birbeck GL. Knowledge, attitudes, behaviors, and practices regarding epilepsy among Zambian clerics. *Epilepsy Behav* 2006 Aug;9(1):83–88. [PubMed: 16713361]
54. Baskind R, Birbeck G. Epilepsy care in Zambia: a study of traditional healers. *Epilepsia* 2005 Jul; 46(7):1121–1126. [PubMed: 16026565]
55. Birbeck GL, Chomba E, Atadzhanov M, Mbewe E, Haworth A. Women's experiences living with epilepsy in Zambia. *Am J Trop Med Hyg* 2008 Aug;79(2):168–172. [PubMed: 18689619]
56. Chomba EN, Haworth A, Atadzhanov M, Mbewe E, Birbeck GL. Zambian health care workers' knowledge, attitudes, beliefs, and practices regarding epilepsy. *Epilepsy Behav* 2007 Feb;10(1): 111–119. [PubMed: 17055341]
57. Mbewe E, Haworth A, Atadzhanov M, Chomba E, Birbeck GL. Epilepsy-related knowledge, attitudes, and practices among Zambian police officers. *Epilepsy Behav* 2007;10:456–462. [PubMed: 17363333]
58. Ab Rahman AF. Awareness and knowledge of epilepsy among students in a Malaysian university. *Seizure* 2005 Dec;14(8):593–596. [PubMed: 16246597]
59. Fernandes PT, Cabral P, Araujo U, Noronha AL, Li LM. Kids' perception about epilepsy. *Epilepsy Behav* 2005 Jun;6(4):601–603. [PubMed: 15907755]
60. Ismail H, Wright J, Rhodes P, Small N. Religious beliefs about causes and treatment of epilepsy. *Br J Gen Pract* 2005 Jan;55(510):26–31. [PubMed: 15667762]
61. Ndoye NF, Sow AD, Diop AG, Sessouma B, Sene-Diouf F, Boissy L, et al. Prevalence of epilepsy its treatment gap and knowledge, attitude and practice of its population in sub-urban Senegal an ILAE/IBE/WHO study. *Seizure* 2005 Mar;14(2):106–111. [PubMed: 15694563]
62. Sirven JI, Lopez RA, Vazquez B, Van Haverbeke P. Que es la Epilepsia? Attitudes and knowledge of epilepsy by Spanish-speaking adults in the United States. *Epilepsy Behav* 2005 Sep;7(2):259–265. [PubMed: 16054871]
63. Zielinska A, Klos E, Talarska D. Youth's knowledge and attitude to epilepsy. *Rocz Akad Med Bialymst* 2005;50 Suppl 1:99–101. [PubMed: 16119638]

Table 1

Demographic and Clinical Characteristics (n=169)

Variable	Values	
<u>Demographic Data</u>		
Age (mean years; range; SD)	35.5 (16–77; 12.6)	
Gender (males; n; %)	85 (50.3%)	
Education (mean years; range; SD)	7.1 (0–12; 3.1)	
Wealth (median US\$ value of owned goods; interquartile range)	\$64 (IQR \$0–1,393)	
<u>Clinical Features</u>		
Seizure Frequency (n; %)	Less than 1 per month 1–3 per month 1 per week Greater than 1 per week Unsure	77 (45.6%) 60 (35.5%) 11 (6.5%) 20 (11.8%) 1 (0.6%)
Has Generalized Tonic–Clonic (n; %)	Always Sometimes Never Unsure	81 (47.9%) 78 (46.2%) 7 (4.1%) 3 (1.8%)
Gets aura prior to seizure (n; %)	Always Sometimes Never Unsure	55 (32.5%) 80 (47.6%) 0 34 (20.1%)
Reports history of significant seizure-related injury [♣] (n;%)	67 (39.6%)	
Seizure stigmata [♠] noted by interviewer (n;%)	63 (37.3%)	

[♣] Defined as an injury requiring hospital admission or which led to prolonged disability or dysfunction

[♠] Physical scars from burns or other injuries the interviewer attributes to seizures and which are commonly assumed to be a sign of incurable epilepsy in Zambia 24. Baskind R, Birbeck GL. Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease. *Epilepsy Behav.* 2005 Aug;7(1):68–3.

Table 2

Disclosure Status, Contagion Beliefs, and Felt Stigma (n=169)

Measure	Values	
<u>Disclosure:</u>		
Do people in your community know that you suffer from epilepsy? (n;%)	Yes, I told them (voluntary)	8 (4.7%)
	Yes, others told them/ they saw me fit forced	147 (87.0%)
	No	14 (8.3%)
<u>Contagion beliefs</u>		
I believe my epilepsy is contagious (n: % agree/true)	36 (21.3%)	
Do people you know believe your condition is contagious? (n; %)	Yes, most people I know	40 (23.7%)
	A few people I know	32 (18.9%)
	No, no one I know	97 (57.4%)
<u>Stigma (answers "yes"=1 point)</u>		
I feel some people are uncomfortable with me because of my epilepsy (n; % yes)	105 (62.1%)	
I feel some people treat me like an inferior person because of my epilepsy (n; % yes)	101 (59.8%)	
I feel some people would prefer to avoid me because of my epilepsy (n;% yes)	98 (58.0%)	
Overall score	Mean 1.8; Median 2.5; Mode 3; Range 0–3; SD 1.3 Score of 0: n=18; 10.7% Score of 1: n=49; 29.2% Score of 2: n=18; 10.7% Score of 3: n=84; 50.0%	

Table 3

Assessing for Predictors of Stigma

	Stigma Score	F (df)	p-value
Age (mean years)	Score of 0: 34.2 years Score of 1: 33.9 years Score of 2: 34.8 years Score of 3: 36.9 years	0.61 (3, 164)	p=0.61
Gender	<u>Mean stigma score</u> Men 1.8 Women 1.9	0.31 (1, 166)	p=0.58
Wealth (mean US\$)	Score of 0: \$1,260 Score of 1: \$846 Score of 2: \$658 Score of 3: \$841	0.92 (3, 160)	p=0.56
Seizure type	<u>Mean stigma score</u> Ever Generalized Tonic Clonic (GTC) 2.0 Never GTC 1.7	1.95 (2, 165)	p=0.15
Seizure frequency	<u>Mean stigma score</u> Less than 1 per month 1.7 1-3 per month 1.9 1 per week 1.5 More than 1 per week 2.3	1.64 (4, 163)	p=0.17
Disclosure status	<u>Mean stigma score</u> Voluntary 1.5 Forced 1.9 None 0.92	3.89 (2, 165)	p=0.02
Personal Contagion Belief	<u>Mean stigma score</u> Present 2.6 Absent 1.3	11.84 (2, 165)	p<0.0001
Community Contagion Belief	<u>Mean stigma score</u> Most 2.0 A few 1.6 None 1.3	3.81 (3, 164)	p=0.01
Stigmata	<u>Mean stigma score</u> Present 2.0 Absent 1.8	1.14 (1, 159)	p=0.29