



Published in final edited form as:

Am J Trop Med Hyg. 2008 August ; 79(2): 168–172.

Women's Experiences Living with Epilepsy in Zambia

Gretchen L. Birbeck*, Elwyn Chomba, Masharip Atadzhanov, Edward Mbewe, and Alan Haworth

Chikankata Health Services Epilepsy Care Team, Mazabuka, Zambia and Michigan State University's International Neurologic and Psychiatric Epidemiology Program, East Lansing, Michigan; Department of Pediatrics and Child Health, University of Zambia, Lusaka, Zambia; Department of Medicine, University of Zambia, Lusaka, Zambia; Chainama Hills Hospital, Lusaka, Zambia; Department of Psychiatry, University of Zambia and Chainama Hills Hospital, Lusaka, Zambia

Abstract

Epilepsy-associated stigma is a well-recognized phenomenon that adversely impacts the lives of people with epilepsy (PWE). The burden of stigma follows power differentials, with socially and economically disenfranchised groups being particularly susceptible. To guide instrument development for quantitative studies, we conducted a series of focus group discussions among PWE and found that women with epilepsy experienced especially adverse social and economic problems because of epilepsy-associated stigma. The social burden of the disease largely outweighed the medical burden. Women revealed seizure worries related to accidental and intentional injury and the risk of breaking taboos as well as limitations in role fulfillment and extremes of social rejection by family and community. Our findings have implications for access to care and care delivery for vulnerable populations with epilepsy.

INTRODUCTION

Epilepsy has long been recognized as a health-related condition that often carries with it a heavy burden of stigma.¹ The very nature of the condition that may involve an abrupt loss of control of ones' bodily functions and senses, sometimes in a manner than appears violent to observers, results in fear and discrimination against people with epilepsy (PWE).² Although epilepsy-associated stigma as a phenomenon has been described in publications from almost every corner of the world,^{2–14} the burden seems to be particularly heavy for PWE in sub-Saharan Africa (SSA), especially rural regions. Epilepsy prevalence in areas of SSA is significantly higher than that of developed regions,^{15–19} the treatment gap (proportion of people with the condition who require treatment but are not receiving it) for epilepsy often exceeds 90% in Africa,²⁰ and traditional belief systems that attribute epilepsy to demon possession, witchcraft, and/or seek to blame the victim²¹ all offer the ideal environment for stigma to flourish.

*Address correspondence to Gretchen L. Birbeck, 324 West Fee Hall, East Lansing, MI 48824. E-mail: Gretchen.Birbeck@ht.msu.edu. Authors' addresses: Gretchen L. Birbeck, Michigan State University's International Neurologic and Psychiatric Epidemiology Program, 324 West Fee Hall, East Lansing, MI 48824, Tel: 517-353-8122, Fax: 517-432-9414, E-mail: Gretchen.Birbeck@ht.msu.edu. Elwyn Chomba, Plot 5643 Lufubu Rd., Kalundu, Lusaka, University Teaching Hospital, P.O. Box RW 1X, Department of Pediatrics and Child Health, Tel: +260-211-254655, E-mail: echomba@zamnet.zm. Masharip Atadzhanov, P.O. Box 51237, Lusaka, Zambia, Tel: 0977775662, E-mail: masharip@yahoo.com. Edward Mbewe, Chainama Hills College Hospital, P.O. Box 30043, Lusaka, No. 1813 Palm Drive Chelston Lusaka, Tel: 0977420775, Fax: 260-1-283824, E-mail: embewe2001@yahoo.com. Alan Haworth, 38 Bwinjifumu Rd., Rhodes Park, Lusaka, Tel: 0977308078, E-mail: haworth@zamnet.zm.

Health-related stigma, characterized by a “spoiled identity,”²² is probably not equally distributed across all individuals in a society.²³ Stigma is a social phenomena influenced by power differentials based on cultural circumstances of birth, sex, resources, etc. As such, one might imagine that the burden of epilepsy-associated stigma is likely to be the greatest for traditionally disempowered groups. In 2003, we conducted a series of focus group discussions involving PWE in Zambia as preparatory work for quantitative knowledge, attitude, and practice (KAP) surveys^{24–27} and a case-control study of the social and economic sequelae of epilepsy.²⁸ The initial primary aims of the focus group discussions were to assure that KAP surveys and case-control studies planned included appropriate items addressing all relevant areas of the lives of PWE and identify the appropriate “power groups” for study, meaning social entities who most strongly moderate or mediate stigma experiences and discrimination for PWE.

MATERIALS AND METHODS

Six focus groups of 8–15 women with epilepsy in each group were held in 2003. Three urban groups were selected from clinic attendees with sampling completed by selection of only one to two women per clinic session and then combining a number of clinics together to form a group in which ideally none of the participants knew one another socially before the focus group met. In the rural region, a population-based registry of PWE was used to randomly select for invitation to the discussions one woman from each village community—again to deter the presence of existing social relationships before the discussions. A written invitation was hand delivered in private to potential participants, and a verbal invitation was simultaneously offered because of potential illiteracy. This work was approved by Michigan State University’s Human Subject Protection Committee and the University of Zambia’s Research Ethics Committee.

Greater than 95% of invitees chose to participate. For women who chose to attend the session, individual written consent was obtained for participation as well as group consent for audio taping. Each focus group was led by two staff fluent in the local language and formally trained in the conduct of focus groups. At least one moderating staff member had prior experience in the conduct of focus group discussions. Each discussion was also attended by a co-investigator who remained silent and only observed without any level of participation.

Audio tapes were translated by a committee consisting of health care and social workers fluent in English and the applicable local language. The transcripts were reviewed by the research investigators for content analysis to identify main themes and were subsequently coded for retrieval and analysis. Because of an underlying interest in quantifying stigma and evaluating the role of specific social entities that may propagate or moderate stigma, we conceptualized the findings in terms of the social setting or specific relationship in which the experience of stigma, discrimination, or deprivation occurred.

RESULTS

Themes identified by consensus during analysis are presented below. Direct quotes translated into English from the recorded and transcribed discussion applicable to the theme are presented in *italics* to illustrate the theme from the direct perspective of a woman with epilepsy in Zambia.

Seizure worries

Women with epilepsy (WWE) in all groups described seizures worries related to three categories:

1. shame caused by inadvertant taboo breaking, 2) accidental injury, and 3) intentional injury inflicted by another person.

Shame/breaking taboos

When I am in an attack, I may be found by a stranger and I may not even be decently covered. Then everyone knows of your problem and you are ashamed.

A common worry women shared was that, during a seizure, their skirt, dress, or chitenge clothing might ride up to reveal their legs and other private regions. Being typically very modest in disclosure of their lower limbs, this was a distressing possibility. Within the Tonga population, the fear of such disclosure was even more marked. Among the Tonga people, tradition dictates that a woman's husband purchases or acquires her undergarments, and the state of her undergarments reflects to some extent the regard her husband holds for her. In such circumstances, a woman who has been abandoned or is being neglected by her husband might have no undergarments or those worn might be in particularly poor condition. Hence, a Tonga WWE could be doubly shamed during a seizure—in addition to the physical exposure, the lack of appropriate underwear would also show a lack of regard or affection from her husband. Most Tonga women felt this was the greater shame.

Generalized seizures are often associated with fecal and/or urinary incontinence, which also causes PWE to break important social taboos. Exposing others to one's bodily fluids is socially prohibited in many Zambian groups. Only relatives within the direct matrilineal line can be thus exposed, and violation of this taboo is potentially punishable by a substantial fine. This caused further worry and for women with frequent seizures also resulted in having only a small number of potentially appropriate relatives to assist them should a seizure occur.

Accidental injury

This disease has caused me a lot of problems. I can't walk around freely. I can't cook because of the fire. I am not free to do things since at any time I could have an attack. I am not even free in my own home. I can't go to draw water alone. I can't bathe alone. All diseases hurt, but this one has really affected my heart.

Drowning, burns, and fractures or lacerations from falls occur very commonly among PWE in Africa.^{19,29} Discussion participants were all too familiar with this reality. Most struggled with whether to continue their usual daily activities and risk significant injury or to abdicate cooking and water-fetching tasks to others in the home. Relinquishing domestic roles caused extreme distress and loss of identity among many women (see *Role fulfillment*). In urban groups, women feared crossing busy streets or traveling in open vehicles because an ill-timed seizure could prove fatal.

Intentional injury

When I am in an attack, anyone who finds me could just take me somewhere. Sell my organs. Assault me. I am not aware and would not be able to defend myself. It is worse in the city, I think.

Women feared intentional injury or theft during a seizure. Some reported having their money taken from them or food goods taken when they experienced a seizure in an urban public setting.

Vulnerability to sexual assault: In addition to feeling vulnerable to assault during a seizure, women expressed explicit concerns that they were particularly vulnerable to sexual assault whenever they were found alone. The traditional “legal” deterrent against sexual assault in Zambia is typically the potential that the rapist will be forced to pay punitive financial restitution to the female rape victim's family (i.e., her husband if she is married or her uncle or father). However, many WWE had already been abandoned by the male who would typically serve as her “protector.” As such, with no male protector, WWE felt that their lack of a

champion was known to all and that any man who wished to sexually assault her knew he could do so without the risk of retribution.

The men, they know. They know which of us is unprotected. Then they can just do as they like and no one will confront them.

Feelings of vulnerability to sexual exploitation resulted in WWE being very reluctant to travel alone. Therefore, a travel companion was required for them to attend monthly epilepsy clinic visits for treatment. The lack of an available, appropriate (i.e., matrilineal relative) traveling companion was cited as a common reason for lapses in epilepsy treatment adherence.

Family response to the PWE

How family members responded to the PWE and their medical condition played a central role in their own self-perceptions as well as their general social and economic well being. Some had supportive families, whereas others experienced extreme rejection. Many participants reported physical abuse in the home. In urban regions, women reported being ejected from family home because of family fears that the landlord would evict all of them if it became known that someone in the household had epilepsy. These women expressed feeling shame and rejection at being “sent back to the village.”

And then my uncle said, “If someone is bewitching you, better they should just kill you.” [stated before he threw her out of the family compound].

My father took care of me and protected me from my mother and brother. But since my father died ... my God has abandoned me. [she went on to describe frequent beatings at the hands of her family members since her father's death].

I had a seizure on the way [to clinic]. My children had to go back to the village for help and my family had to come and collect me in a scotch cart. My husband says he won't divorce me as this problem started after we were already married, but one day he will tire of this and leave.

My brother gave me to the man without labola [bride price usually paid] and said, “Just take her. She has no value for us” [the woman was presently unmarried but living with the man she had been “given” to. She reported physical abuse and neglect in the relationship but felt she had no where else to go].

Role fulfillment

Even when a woman's family was accepting and supportive, her capacity for role fulfillment as a mother and wife was often negatively impacted by role limitations encountered in efforts to avoid accidental injury, an inability to find a marital partner, and disadvantage in employment.

Martial relationships—Women who were unmarried when they developed epilepsy (or their epilepsy was disclosed to the community) had difficulty finding marriage partners.

Most of my problems are due to people talking about me. I would like to marry again, but whenever someone shows interest, people talk to that man and tell him about my problem and so I haven't had any offers of marriage.

Married women had either been abandoned or lived in daily fear of being abandoned by their husbands.

If others know of my condition, they may tell my husband to leave me. I didn't ask for this problem. People don't realize that I didn't ask for it. Maybe God should take my life away.

Abandoned WWE often also lost their children, who were taken by the husband's family.

In 2001, my husband divorced me because of my seizures. My child was only 1 year old at that time and my husband took my child when he left.

If the marriage had not produced children, the labola (bride price) was reclaimed. Consequently, the woman's family might refuse to take her back into her home of origin. In polygamous marriages, formal divorce was uncommon, but fiscal abandonment and sexual rejection resulted in extreme poverty and great public humiliation.

My husband supports me. But since he took a second wife, he never lies with me. My husband's family and the second wife are afraid she will get this condition from me. They think my condition shames the family. People tell my husband he should abandon me. Sometimes I drink.

My husband ... he won't give me even K100 [approximately US\$0.03]. He won't divorce me though because we have five children.

I am the third wife and once I had a seizure while I was having relations with my husband. Since then he has stopped coming to me. I count the days, but he doesn't come to me and I have become a laughing stock. Because he does not come to my bed, things are not ok. He is only buying bed sheets for the other wives. But when I have a seizure I am grateful that he sends a scotch cart and brings me to the hospital.

Women also complained of sexual dysfunction with loss of libido but were uncertain if this was caused by the seizures, the stress of living with epilepsy, or the epilepsy medications.

When you are having seizures, you don't have desire for a man.

Childbearing and rearing—Fear and ambivalence regarding motherhood predominated among WWE. They feared that their children might be taken from them. They also worried about the consequences of seizures during pregnancy, the possibility of passing epilepsy onto their children, and the risk of injuring their child during a fit. (Because infants are traditionally carried on the mother's back, even an otherwise brief seizure could indeed result in significant pediatric injury. Although not common, infants and toddlers of WWE have presented for care to our local clinics after such an injury.)

We [meaning WWE] should not have children. The seizures can get worse when we are pregnant and the work of being a mother can also worsen this problem.

Every time I am pregnant the seizures get worse. If I fit when I am pregnant, then maybe my child will have this problem, too.

Maybe if I breastfeed, there will be problems.

... And maybe one day I will get angry and drop my baby. What kind of a mother cannot care for her own child? I don't want relations with my husband and I might hurt my own child during a fit. Maybe one day I will just find my baby dead because I threw her away.

Employment—Opportunities in both the formal and informal employment sectors were limited for WWE. Seizure worries placed limitations on employment if exposure to fire, deep water, and/or heights were avoided. Women who undertook employment as casual farm workers noted that both their seizures and their medications made them slow and unable to keep up with the required productivity. Entrepreneurial attempts at selling local goods, even if originally successful, failed if the buying public knew the seller was a PWE.

Most women used in the formal sector expected to have their employment terminated if they had a seizure at work, and this was the general experience among those who had. An inability or the loss of the ability to contribute fiscally to the family unit had a negative impact on their marital relationship. Participants alluded to the necessity of exchanging sex for survival goods.

My marriage has changed. I don't work now and cannot bring money like before. And because of my epilepsy, I can't find work ... because my condition is known, no one will hire me.

Social role in the broader community—Forced disclosure occurred for most WWE because of a public seizure. Consequently, many of them spoke about their lives in terms of before and after the “disclosure” day—because after this day, everything changed for them.

And before I was even awake, before I could even clean myself, people three villages away knew of my problem.

Once labeled as a PWE, women noted that no one visited them socially anymore. Some reported even being taunted by children, which was particularly humiliating.

In town there was too much talk and even the children ridiculed me there. Then the children in town disrespected me and I cried a lot. I became so sad that I could barely force myself out of bed to do my duties.

Because of the epilepsy, people won't sit next to me. Even my family has rejected me.

Long-standing social isolation had been felt by many of the WWE who attended the discussions. During a mid-day meal held for rural participants who had to travel far, some women wept when they realized they would be allowed to “share the pot” with others rather than being expected to take their meals alone.

DISCUSSION

Although focus groups were conducted with various affected persons including groups of men with epilepsy, WWE, youths with epilepsy, and the parents of children with epilepsy, the most distressing personal stories shared with us were brought forward during the focus group discussions held with women. As health care providers with many years' experience caring for WWE, we were shocked and saddened by the reality of their lives. Many, perhaps most, of these realities had never been shared with us in the clinical setting, although the circumstances described were very relevant to our attempts to provide clinical services to this vulnerable population. As a traditionally disempowered population, women in this region of Zambia, where polygamy remains common, are particularly devalued. This may at least partially explain the severity of social deprivation and stigmatization described.

Insights gained from the focus group discussions played a critical role in the development of the quantitative aspects of our research program. Invariably all of the concerns and issues brought forward by women in the discussions were shown to be factors that proved statistically significant in our quantitative efforts.²⁸ However, such static questions and number-driven answers fail to fully communicate the life experience of being a WWE in Zambia.

Within the framework of most medical encounters, many broader social issues and circumstances remain unspoken. Although actively addressing the social and economic consequences of a medical condition may lie outside the scope of the clinician's responsibility, some understanding of the social context of the medical condition being treated from the patient's perspective is essential if effective clinical intervention programs are to be developed and implemented. This is especially true for stigmatized health conditions.

Stigma impacts a person's ability to access and adhere to medical treatment, erodes their quality of life, and may threaten their basic survival. Quantitative studies of PWE in this region have shown that WWE are less likely to use basic health services, have poorer food security, and are more likely to experience sexual assault than their peers unaffected by a health-related stigma.²⁸ We did not anticipate the depth and breadth of information that would be gained. This qualitative study provided significant insights into the social factors that mediate stigma and directed the development of the quantitative studies that followed. For example, additional questions were added to the planned socio-economic study to assess whether women with epilepsy are indeed more vulnerable to sexual assault. The rape fears expressed by WWE were not unfounded. In our case-control study, we found 20% of WWE had experienced rape compared with 3% of women with a non-stigmatized chronic medical condition.²⁸ All KAP surveys included, near the end of the questionnaire, a question regarding whether the respondent has a family member with epilepsy, and the KAP studies were expanded to include "employers," a power group entity. Activities to decrease the social and economic burden of epilepsy and epilepsy-related stigma will need to include empowerment efforts for WWE, but engaging the power groups whose enacted stigma presents the greatest burden (i.e., family members and employers for WWE, teachers for children with epilepsy) will be necessary components of any successful intervention program.

The burden of epilepsy-associated stigma follows power differentials. We found in the focus group discussions that stigma and discrimination were reported most often by women in polygamous marriages, those who had the least education, and those who had lost their employment as a result of their condition. Men with epilepsy who participated in our focus group discussions were distressed at the financial cost of the disorder and its disruption to their lives, but familial rejection and spousal abandonment were not reported. As noted by Parker and Aggleton³⁰ in their studies of HIV/AIDS, "stigma feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality." For WWE in Zambia, the social and economic impact of epilepsy far outweighed the biomedical burden of disease.

Acknowledgements

We thank the Epilepsy Association of Zambia and the Chikankata Epilepsy Care Team for logistic support and the women who participated in the focus group discussions and were so open in their exchanges.

Financial support: This work was supported by NIH Grants NS48060 and NS46086. During this work, GB also received support as a Charles E. Culpeper Medical Scholar through the Goldman Philanthropic Partnerships.

References

1. Scambler G, Hopkins A. Being epileptic: coming to terms with stigma. *Social Health Illness* 1986;8:26–43.
2. Harden CL, Kossoy A, Vera S, Nikolov B. Reaction to epilepsy in the workplace. *Epilepsia* 2004;45:1134–1140. [PubMed: 15329079]
3. Aziz H, Akhtar SW, Hasan KZ. Epilepsy in Pakistan: stigma and psychosocial problems. A population-based epidemiologic study. *Epilepsia* 1997;38:1069–1073. [PubMed: 9579952]
4. Baker G, Brooks J, Buck D, Jacoby A. The Stigma of Epilepsy: A European Perspective. *Epilepsia* 1999;41:98–104. [PubMed: 10643931]
5. Devinsky O, Westbrook L, Cramer J, Glassman M, Perrine K, Camfield C. Risk factors for poor health-related quality of life in adolescents with epilepsy. *Epilepsia* 1999;40:1715–1720. [PubMed: 10612334]
6. Herodes M, Oun A, Haldre S, Kaasik AE. Epilepsy in Estonia: a quality-of-life study. *Epilepsia* 2001;42:1061–1073. [PubMed: 11554894]
7. Jacoby A. Felt versus enacted stigma: a concept revisited. Evidence from a study of people with epilepsy in remission. *Soc Sci Med* 1994;38:269–274. [PubMed: 8140453]

8. Link, B.; Phelan, J. Bethesda, MD: 2001 [Accessed June 22, 2008]. On Stigma and Its Public Health Implications. *Stigma and Global Health: Developing a Research Agenda*. Available at: <http://www.stigmaconference.nih.gov/LinkPaper.htm>
9. Diop AG, de Boer HM, Mandlhate C, Prilipko L, Meinardi H. The global campaign against epilepsy in Africa. *Acta Trop* 2003;87:149–159. [PubMed: 12781390]
10. Prpic I, Korotaj Z, Vlastic-Cicvaric I, Paucic-Kirincic E, Valerjev A, Tomac V. Teachers' opinions about capabilities and behavior of children with epilepsy. *Epilepsy Behav* 2003;4:142–145. [PubMed: 12697138]
11. 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;45:1405–1415. [PubMed: 15509242]
12. Baskind R, Birbeck GL. Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease. *Epilepsy Behav* 2005;7:68–73. [PubMed: 15978874]
13. Diamantopoulos N, Kaleyias J, Tzoufi M, Kotsalis C. A survey of public awareness, understanding, and attitudes toward epilepsy in Greece. *Epilepsia* 2006;47:2154–2164. [PubMed: 17201717]
14. Adewuya AO, Oseni SB, Okeniyi JA. School performance of Nigerian adolescents with epilepsy. *Epilepsia* 2006;47:415–420. [PubMed: 16499769]
15. Birbeck GL, Kalichi EM. Epilepsy prevalence in rural Zambia: a door-to-door survey. *Trop Med Int Health* 2004;9:92–95. [PubMed: 14728612]
16. Kaiser C, Asaba G, Leichsenring M, Kabagambe G. High incidence of epilepsy related to onchocerciasis in West Uganda. *Epilepsy Res* 1998;30:247–251. [PubMed: 9657652]
17. Longe AC, Osuntokun BO. Prevalence of neurological disorders in Udo, a rural community in southern Nigeria. *Trop Geogr Med* 1989;41:36–40. [PubMed: 2763344]
18. Osuntokun BO, Adeuja AO, Nottidge VA, Bademosi O, Olumide A, Ige O, Yaria F, Bolis CL, Schoenberg BS. Prevalence of the epilepsies in Nigerian Africans: a community-based study. *Epilepsia* 1987;28:272–279. [PubMed: 3582291]
19. Jilek-Aall L, Rwiza HT. Prognosis of epilepsy in a rural African community: a 30-year follow-up of 164 patients in an outpatient clinic in rural Tanzania. *Epilepsia* 1992;33:645–650. [PubMed: 1628578]
20. Meyer A, Birbeck G. Determinants of the epilepsy treatment gap in developing countries. *Neurology* 2006;66:A343.
21. Baskind R, Birbeck G. Epilepsy care in Zambia: a study of traditional healers. *Epilepsia* 2005;46:1121–1126. [PubMed: 16026565]
22. Goffman, E. *Notes on the Management of Spoiled Identity*. Englewood Cliffs: Penguin, Harmondsworth; 1963.
23. Report of the Research Workshop on Health-Related Stigma and Discrimination. 2004 [Accessed June 22, 2008]. Available at: <http://www.kit.nl/smartsite.shtml?ch=&id=2546>
24. Atadzhanov M, Chomba E, Haworth A, Mbewe E, Birbeck GL. Knowledge, attitudes, behaviors, and practices regarding epilepsy among Zambian clerics. *Epilepsy Behav* 2006;9:83–88. [PubMed: 16713361]
25. Birbeck GL, Chomba E, Atadzhanov M, Mbewe E, Haworth A. Zambian teachers: what do they know about epilepsy and how can we work with them to decrease stigma? *Epilepsy Behav* 2006;9:275–280. [PubMed: 16877045]
26. Chomba EN, Haworth A, Atadzhanov M, Mbewe E, Birbeck GL. Zambian health care workers' knowledge, attitudes, beliefs, and practices regarding epilepsy. *Epilepsy Behav* 2007;10:111–119. [PubMed: 17055341]
27. 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]
28. 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;6:39–44. [PubMed: 17166800]
29. Birbeck GL. Seizures in rural Zambia. *Epilepsia* 2000;41:277–281. [PubMed: 10714398]

30. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med* 2003;57:13–24. [PubMed: 12753813]