

Review

Epilepsy-associated stigma in sub-Saharan Africa: The social landscape of a disease

Roy Baskind^a, Gretchen L. Birbeck^{b,c,*}

^a Department of Neurology and Neurosurgery, McGill University, Montreal, Quebec, Canada

^b Chikankata Health Services, Epilepsy Care Team, Mazabuka, Zambia

^c Departments of Neurology, Epidemiology, and African Studies, Michigan State University, East Lansing, MI, USA

Received 19 April 2005; accepted 20 April 2005

Available online 22 June 2005

Abstract

Many studies in developed regions of the world have confirmed that stigma contributes substantially to the psychological and social burden of epilepsy. Relatively few studies of epilepsy-associated stigma have been conducted in Africa, where much of the world's burden of epilepsy exists. In sub-Saharan Africa (SSA), particularly in rural regions, close family ties, communal living situations, and traditional belief systems undoubtedly influence the expression of stigmatization. A review of the epidemiologic, anthropologic, and sociologic studies of epilepsy in SSA provides significant insights into how people with epilepsy (PWE) are perceived by their communities and families and how these perceptions translate into limited social and economic opportunities and possibly worsen the physical vulnerability of PWE in this region. The medical community is not exempt from the social process of stigmatization, and poor public health infrastructure and medical services undoubtedly contribute to the cycle of epilepsy-associated stigma through wide treatment gaps, poor seizure control, and high rates of seizure-related injury. In this review, we extrapolate data from existing studies of epilepsy in SSA coupled with our own experience providing epilepsy care in the region to give an overview of the social landscape of this common, devastating condition.

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Keywords: Stigma; Epilepsy; Treatment gap; Contagion; Traditional healers

1. Introduction

Stigma has long been recognized as a major burden to people with epilepsy (PWE) and their families [1,2]. Nowhere is epilepsy-associated stigma more disabling than in sub-Saharan Africa (SSA), where epilepsy rates far exceed those in developed countries [3–6]. In SSA, the combination of poverty, social role expectations, limited medical care, and traditional beliefs coalesce to severely limit the lives of PWE. Epidemiologic and clinical research conducted over the past 20 years in several African countries has provided significant insight into the plight of PWE. The magnitude of the problem com-

pels us to develop interventions aimed at decreasing the burden of epilepsy-associated stigma in this region of the world.

Stigma associated with epilepsy has a profound impact on quality of life in developed as well as developing regions [7–10]. The nature and degree of this stigma are not uniform, even within small communities, and vary depending on an individual's premorbid/baseline status within society, as well as societal conceptualization of the condition (i.e., tendency to blame vs sympathize with the sufferer). The nature and degree of stigma are influenced by the clinical course, drug side effects, age, gender, education, and employment status [11–16]. Furthermore, the capacity to impose stigma on someone depends on power differences [17]. Excellent reviews of epilepsy-associated

* Corresponding author. Fax: +1 517 432 9414.

E-mail address: gretchen.birbeck@ht.msu.edu (G.L. Birbeck).

stigma from the United States and United Kingdom are available [7,18]. Clearly, the social experience of being a person with epilepsy is inextricable from the geopolitical and social context of the sufferer [8,19]. By drawing on our own work as well as literature from social psychologists, sociologists, and clinicians who have studied epilepsy, we outline the social landscape of epilepsy in SSA. Although generalities about such a large, heterogeneous geographic area are inherently imperfect, certain common themes appear valid based on their consistency across the region.

2. Research methods and terminology

The epidemiology of epilepsy in SSA has been assessed in several population-based studies and underscores the public health impact of this common condition. Similar quantitative descriptions of epilepsy-associated stigma, however, require the development of an instrument for measuring stigma in a meaningful way. A simple three-question tool for assessing the level of patient-perceived stigma has been developed and validated in a European population [16]:

Because of my epilepsy:

- | | | |
|--|-----|----|
| (a) I feel that some people are uncomfortable with me. | Yes | No |
| (b) I feel some people treat me like an inferior person. | Yes | No |
| (c) I feel some people would prefer to avoid me. | Yes | No |

Development of an ecologically valid measure for use in SSA would first require qualitative studies to fully explore the impact of epilepsy in this social and medical context [20,21]. One need only read the superb narrative description of the despised and devalued PWE that Jilek-Aall and colleagues encountered in 1965 in Tanzania to appreciate the importance of clinical observation in understanding stigma [22]. Only through combining such narrative information with quantitative work can we begin to appreciate the realities of living with epilepsy in SSA.

Stigma research has generally characterized stigma as *felt* versus *enacted*. Enacted stigma manifests as discrimination against the stigmatized person imposed by others, whereas felt stigma is the fear of enacted stigma experienced by the stigmatized person. Felt stigma may result in the stigmatized person volitionally limiting their life experiences and opportunities in an effort to avoid enacted stigma. Courtesy stigma is the “stigma by association” experienced by individuals in close social or physical proximity to someone who is stigmatized [23]. Courtesy stigmas may have components of felt or enacted stigma. Data from developed countries indicate

that today felt stigma may be more limiting for PWE than enacted stigma, but this probably is not true in SSA, where the burden of enacted stigma remains substantial [9].

3. Medical context and consequences

The treatment gap among PWE, the proportion of people who warrant medical care but are not receiving anticonvulsants, ranges from 65 to 95% in SSA and is highest in rural areas [24,25]. This gap results from several factors including belief systems that attribute epilepsy to supernatural rather than medical causes, a dearth of health care facilities, health care workers who receive inadequate training in epilepsy diagnosis and care, and the substantial direct and indirect costs of care seeking [5,6,26,27]. The vicious cycle of epilepsy-induced poverty further limiting the capacity of PWE to access care cannot be underestimated. As a result of the treatment gap, many PWE in SSA experience frequent, uncontrolled seizures in a physical environment where such seizures may result in severe burns, drowning, and fractures [22,24].

As has been widely described [28–36], the most obvious and feared stigmata of epilepsy in Africa is burns. Much of the cooking is done over open fires, and during cool winter months people spend long hours next to the fire for warmth. Hence, a common complication of epilepsy is severe burns. Burn scars are seen as an ominous mark of intractable epilepsy. Many traditional healers interpret burns as having sealed the fate of an epileptic patient [37].

4. Belief systems

Reports from SSA universally indicate that people believe seizures to be contagious, spread by saliva, urine, feces, or flatus expelled during a convulsion [38–40]. The fear of contagion results in enacted stigma in the form of isolation and bystanders’ unwillingness to intervene in preventing injury. Profound psychological and physical disability may result. As noted above, burns are the most overt example of this.

Seizures and epilepsy are attributed to several other causative factors besides direct contagion. Supernatural beliefs, such as witchcraft, are frequently cited as causing seizures. A person versed in magical arts may “put a curse” on someone, thereby draining the family’s precious financial resources [37]. When patients and/or their families hold supernatural beliefs regarding seizures, care seeking will be directed toward traditional healers rather than hospital or clinic-based care. Furthermore, seeking care from traditional healers may lead to delayed medical treatment. Children with malaria-

induced febrile seizures whose parents hold supernatural beliefs regarding seizures are more likely to be treated with traditional medicines rather than medical treatments from local clinics. This has health implications for the children who receive delayed care, as they exhibit higher malarial parasitemia at presentation and require longer hospitalizations than children with febrile seizures whose parents recognized the association between seizures and hyperthermia [41].

When epilepsy is attributed to supernatural causes, care seeking often does not include attendance at local medical clinics. In one large rural region of Zambia, less than 4% of PWE identified in a door-to-door survey had sought care from medical personnel, though all had been seen by at least one traditional healer [4].

A familial propensity toward seizures is recognized and may result in overly aggressive management of otherwise benign, provoked febrile seizures. For example, bush teas,¹ a common treatment given to adults with epilepsy by traditional healers, may be given to children during febrile seizures. Generally, the tea is given by a parent with epilepsy who is very concerned that the febrile seizure may be a prelude to later epilepsy in their child. But when bush tea is given to an unconscious child, severe complications including oral burns and aspiration pneumonia can occur [41].

5. Community context

In most of SSA, life is tightly constrained by poverty, poor education, a heavy burden of infectious diseases, and a drastically short life expectancy. Past and present wars and recent famine have further eroded an already difficult existence for most people in this part of the world. Strong extended family and communal ties have traditionally provided much of the strength that has allowed people to survive and even thrive in this challenging environment. In this context, the central focus of one's place within the community must be appreciated. For PWE in Africa, self-perceptions are determined largely by one's place within the community and family unit. In rural areas, people rely on one another to complete the daily tasks necessary for survival (fetching water, cutting firewood, growing food). Manual labor is divided among all members of the extended family. The social worth of an individual may be determined largely by his or her ability to fulfill this unwritten social contract [42].

The nature of epilepsy places individuals with uncontrolled seizures in a precarious position. They must either defer some of their personal duties to others (and thereby fail to fulfill their social role within the

group) or undertake the expected tasks at significant risk of injury. If PWE are unable to complete the manual chores and contribute to their social group in the expected ways, their social value may consequently diminish further, increasing stigma and decreasing the social and economic opportunities for the individual. Alternatively, the physical disability and stigmata that may result from seizure-related injuries are substantial. Where heating and cooking occur over open flames, burn scars have long been recognized as epilepsy-associated stigmata [43], and the occurrence of burns during a seizure is thought to signify the incurability of the condition [37].

6. Socioeconomic impact

PWE in SSA are negatively impacted not only by the need to limit their productive activities to avoid seizure-related injuries, but also by restrictions on other important social and economic functions due to epilepsy-associated stigma. Osuntokun and Odeku described patients abandoned by their wives because of nocturnal enuresis due to convulsions [44]. Jilek-Aall et al. found PWE unwilling to discuss their disadvantaged marital choices, but community representatives readily reported that females with epilepsy were viewed as poor wives. These community informants reported that women with epilepsy are unable to properly take care of children, cook on a fire, and fetch water, making them poor choices for a wife [22]. Quantitative work in rural southern Zambia has shown that in polygamous regions, men with epilepsy are less likely to marry and women with epilepsy, though not less likely to marry, are less likely to be the first wife² [24].

Marital limitations carry particularly dire consequences for women with epilepsy, as unmarried adult females are particularly vulnerable to sexual exploitation, physical abuse, and extreme poverty. Anecdotal reports suggest that women with epilepsy in SSA have to resort to exchanging sex for food and shelter more frequently than their peers. If this is true, then epilepsy may be a de facto risk factor for HIV/AIDS in the region. Further study of this is clearly warranted.

In addition to limited marital options, data from a hospital-based study indicate that PWE of normal intelligence receive significantly less education than their sex-matched siblings [24]. Lost opportunities for education may be due to parental choice. As most families cannot afford to educate all children in the family, parents may choose not to invest in a child with epilepsy whose employment options might be limited. Alternatively, parents may decide to remove a child from school to

¹ Bush teas are teas made from boiling a local root or leaves and decanting off the liquid.

² Generally being the first wife is the most prestigious position, and later wives are somewhat subject to her.

avoid the embarrassment that might occur if the child has a seizure in this public setting. Several reports indicate that teachers frequently expel children with epilepsy from school solely because of their seizure disorder [44–46]. Regardless of the reason why education is abbreviated, PWE who receive less education than their peers must deal with this disadvantage for life. Given high rates of unemployment in SSA cities, limited education may be particularly disadvantageous.

The economic impact of epilepsy may adversely affect a person's ability to maintain even the most basic survival commodity. Where food is scarce, a "pecking order" is often maintained. Able-bodied adult males generally eat first. In 2003, in the midst of a famine in southern Zambia, PWE experienced significant weight loss. More than 80% of these patients had a >5-kg weight loss and almost 20% showed signs of severe malnutrition. Some of these patients reported being denied donor food aid because they were excluded from the local census; others reported blatant discrimination, attributing this to their devalued status as epileptics [47]. Although anticonvulsant drug supplies were not interrupted during the famine, adherence to medication regimens was poor, as most PWE reported difficulty taking phenobarbital without food.

Besides basic biological needs, social development and contacts are adversely effected by epilepsy. Social isolation can certainly result from epilepsy-associated stigma. Giel found PWE living in cemeteries and church courtyards in Ethiopia [40]. Jilek-Aall et al. found PWE were often "tucked away in remote areas by their families" [48], seeking refuge together after having involuntarily left their homes. These may be more extreme examples, but social isolation is often present on a smaller scale. PWE in SSA are frequently required to use separate eating utensils, eat from a different dish, or use separate sleeping quarters away from the rest of the household (i.e., they are physically segregated from the community). PWE are often hidden from visitors.

7. Forced disclosure

Studies among PWE in developed regions indicate that many deal with stigma by "information control": they manage potential stigma by selectively choosing to whom they reveal their condition [49–51]. However, in SSA, close social ties and relatively open housing mean that PWE have less ability to conceal their condition. Villages typically comprise large extended families. Neighboring villages are within short walks of one another. Common water sources for drinking, bathing, and laundering clothes are shared by large numbers of people. Life is lived under the constant watch of one's neighbors. Concealing convulsions is far more difficult in this environment. Forced disclosure of this nature

may partially explain the differences in quality of life experienced by people in rural versus urban settings in SSA [45].

8. Rural versus urban differences

Epilepsy-associated disability varies between rural and urban regions, with rural residents suffering greater disability. In a study comparing functional status among rural Zambians and neighboring urban Zimbabweans, the rural cohort showed higher rates of disability [45]. A possible mediator of the greater rural burden may be the "downward social drift" effect, whereby PWE leave the urban areas for life in rural regions where they may be more likely to receive support from the extended family. Alternatively, the treatment gap is probably narrower in urban regions, where more medical facilities are geographically accessible.

9. Courtesy stigma

Stigma in SSA extends beyond the individual to family members and other close associates [8,52]. Jilek-Aall noted the stigmatization of a whole tribe based partially on high rates of epilepsy [52]. Giel described significant familial dysfunction after convulsions in some of his cases from Ethiopia [40]. Courtesy stigma may even extend beyond the family to include health care workers who provide services to PWE [53].

10. Health care workers' role in epilepsy-associated stigma

One aspect of epilepsy care that is perhaps underappreciated in accounting for epilepsy-associated stigma is physician and other health care providers' discomfort with diagnosing seizures and prescribing and managing antiepileptic drugs [54]. Even practitioners in resource-rich countries may have little specialty training [55]. This problem is especially pronounced in African settings, where most primary health care providers receive little training in neurological care and have no recourse to specialists [54]. Possibly due to limited formal neurological education, some Zambian physicians attribute some seizures to supernatural causes [37]. Unfortunately, these beliefs may influence their willingness to provide epilepsy care and the quality and content of that care.

11. Traditional healers: mediating stigma

People in SSA rely heavily on traditional healers for their health care needs, and PWE have almost always

sought care from healers before they are seen by the formal medical system [37]. Seizures are widely associated with witchcraft, and traditional healers are seen as having the power to mediate witchcraft. Some traditional healers endorse an explanation for epilepsy in which the whole family unit is seen as the victim [37]. This may serve to foster protective feelings toward the PWE. Alternatively, as witchcraft is commonly believed to be a result of malice incurred by wronging one's enemy, PWE may be seen as having somehow "earned" their ailment through wrongdoing. The attribution of responsibility of the sufferer for their ailment is posited as the key ingredient in some theories of stigma, with greater stigma occurring when the individual is somehow blamed for their stigmatized condition [56,57].

Another widely held belief is that breaking taboos may cause seizures. Angered ancestors may send the ailment as a punishment for socially inappropriate behavior. Again, PWE, or those close to them, may be thought to somehow be responsible for their lot due to socially disdained behavior. Fundamental theories of stigma [58] emphasize its important functional role as delineating between the normal and the deviant in society. The linking of epilepsy to deviant social behavior is a striking example of this premise.

Traditional healers are certainly key figures in mediating stigma. On some level they may perpetuate and indeed profit from stigmatizing beliefs about witchcraft causing epilepsy. By identifying socially inappropriate behavior (either of the person with epilepsy or people close to them) and interpreting this as the cause of seizures, they may be powerful enforcers of socially appropriate behavior. The practice of "immunizing" the family members of PWE against the perceived contagion may serve a protective function [37].

12. Final thoughts

Epilepsy-associated stigma is a devastating burden to PWE in SSA. Interventions to decrease stigma are desperately needed. Public education is generally advocated as the best approach to stigma reduction, but given the deeply ingrained beliefs about epilepsy etiology and the far-reaching social, medical, and economic impact of epilepsy in this environment, stigma-reducing interventions must be thoughtfully developed on the basis of qualitative and quantitative assessments of the factors mediating stigma in this region. Because limited resources are available for undertaking stigma-reducing interventions, interventions that focus on the most vulnerable (e.g., women and children) may prove to be the most cost effective. A better understanding of how the burden of epilepsy-associated stigma intersects with the devastation imparted by the ongoing AIDS epidemic in this region is also required.

Acknowledgment

We would like to acknowledge the following grant: NIH/NINDS R21 NS48060.

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