



The role of foundations and ngos in mitigating epilepsy stigma. Le rôle des fondations et des ong dans l'atténuation de la stigmatisation de l'épilepsie.



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Abstract

Epilepsy is a neurological condition characterized by recurring seizures, affecting an estimated 65 million people worldwide, the large majority of whom live in low- and middle-income countries. In these lower-income regions, people with epilepsy (PWE) frequently face widespread and severe social stigma that dramatically reduces their quality of life and that of their households. Because the social consequences can even exceed the medical, stigma reduction efforts are an essential part of improving the quality of life for PWE. "Resource organizations" (such as funding foundations) and "implementors" (such as epilepsy-focused NGOs) can partner to play a critical role in helping to increase understanding of epilepsy and reduce its harmful effects.

Three program implementors in Africa are using general sensitization and targeted education as primary methods to curb the effects of stigma. These methods are designed and delivered according to local context and target group. The implementors report that much of the stigma problem is rooted in the common belief that epilepsy has a spiritual cause. A general lack of understanding of basic medical facts (causes, cures, etc.) about epilepsy is also widespread. Common methods used to address the problem include awareness campaigns, door-to-door outreach, media promotions and printed literature. However, NGO implementors report scarce resources as a major limiting factor in their efforts.

As the wider community gains awareness that epilepsy is a medical condition that can often be successfully treated, healthcare providers support awareness and education efforts by helping reduce or eliminate seizures. Any efforts to reduce stigma should link access to diagnostic and treatment resources to support effective epilepsy management. Because efforts around epilepsy in low-income regions are substantially under-resourced, foundations and other resource organizations are critically needed to expand the work being done.

Keywords: Awareness - Epilepsy - Seizures - Stigma - Treatment Gap.

Résumé

L'épilepsie est une maladie neurologique caractérisée par des crises récurrentes, affectant environ 65 millions de personnes dans le monde, dont la grande majorité vit dans des pays à revenu faible ou intermédiaire. Dans ces régions à faible revenu, les personnes atteintes d'épilepsie (PWE) sont fréquemment confrontées à une stigmatisation sociale généralisée et grave qui réduit considérablement leur qualité de vie et celle de leurs ménages. Parce que les conséquences sociales peuvent même dépasser les conséquences médicales, les efforts de réduction de la stigmatisation sont un élément essentiel de l'améliora-

tion de la qualité de vie des PWE. Les « organisations de ressources » (telles que les fondations de financement) et les « exécutants » (telles que les ONG axées sur l'épilepsie) peuvent s'associer pour jouer un rôle essentiel en aidant à mieux comprendre l'épilepsie et à réduire ses effets nocifs.

Trois personnes chargées de la mise en œuvre du programme en Afrique utilisent la sensibilisation générale et l'éducation ciblée comme méthodes principales pour réduire les effets de la stigmatisation. Ces méthodes sont conçues et mises en œuvre en fonction du contexte local et du groupe cible. Les réalisateurs rapportent qu'une grande partie du problème de stigmatisation est enracinée dans la croyance commune que l'épilepsie a une cause spirituelle. Un manque général de compréhension des faits médicaux de base (causes, remèdes, etc.) sur l'épilepsie est également répandu. Les méthodes courantes utilisées pour résoudre le problème comprennent les campagnes de sensibilisation, le porte-à-porte, les promotions médiatiques et la littérature imprimée. Cependant, les responsables de la mise en œuvre des ONG signalent que les ressources limitées sont un facteur limitant majeur dans leurs efforts.

Alors que la communauté au sens large prend conscience que l'épilepsie est une maladie qui peut souvent être traitée avec succès, les prestataires de soins de santé soutiennent les efforts de sensibilisation et d'éducation en aidant à réduire ou à éliminer les crises. Tout effort visant à réduire la stigmatisation devrait lier l'accès aux ressources de diagnostic et de traitement pour soutenir une gestion efficace de l'épilepsie. Étant donné que les efforts autour de l'épilepsie dans les régions à faible revenu manquent considérablement de ressources, des fondations et d'autres organisations de ressources sont indispensables pour étendre le travail en cours.

Mots-clés : Convulsions - Écart de traitement - Épilepsie - Sensibilisation - Stigmatisation.

Introduction

Epilepsy can be controlled in 70% of patients through knowledgeable health care providers, proper diagnosis, and the right medication(s).¹ However, approximately 80% of the estimated 65 million people with epilepsy live in low- and middle-income countries (LMICs) where the treatment gap averages 75%.² Larger gaps are reported in many African countries.³ Untreated epilepsy results in a range of physical effects that include impaired brain development in children, secondary injuries from falls, the risk of early death, and others. Beyond the physical, there are severe social consequences associated with epilepsy, particularly in lower-income regions where misconceptions around epilepsy are widespread. Human rights violations are common among PWE and include being denied an education, employment and the right to marry.⁴

Seizures are often understood to be the result of demon possession leading to PWE being shunned or even killed by their communities.⁵ Risks of physical and sexual abuse are higher among PWE (particularly women) compared to other conditions,⁶ and abuse may come from family members as well as the community. PWE are vulnerable to crimes such as theft, during or after a seizure.

As noted by the World Health Organization (WHO), epilepsy stigma and discrimination are often more difficult to overcome than the seizures themselves.⁷ In a vicious cycle, an individual who experiences social stigma because of seizures often avoids seeking the treatment that can reduce or eliminate the seizures to avoid being associated with epilepsy. For this reason, epilepsy is often called an “invisible” disease. Further compounding the problem, those who pursue treatment may even experience prejudice in a medical setting, an environment where the patient should feel secure.⁸

Epilepsy Stigma

Social stigma can be viewed as an outcome of ignorance mixed with fear and/or prejudice. In addition to the epilepsy stigma seen globally — in education, employment, relationships, etc. — some types of social stigma appear specific to characteristics of traditional cultures in many lower-income countries. For example, the common misbelief that epilepsy is a spiritual condition leads to PWE being perceived as sinful, possessed, cursed or bewitched. Consequently, the person may be ignored, shamed, mistreated, or even killed.

This category of stigma places a heavier burden on the PWE than on the social group which lacks understanding. The misconception of spiritual origins also leads individuals to seek cures from traditional and faith healers rather than medical providers. Pursuit of alternative healing significantly delays medical treatment. Findings of the Guinea Epilepsy Project indicate that a majority of PWE in Guinea sought care from traditional healers for more than three years on average before seeking medical care.⁹ Traditional healers are unable to resolve symptoms, yet they often involve a higher financial cost than medical treatment and deplete the financial resources of poor families.¹⁰

Another common misconception within many cultures is that epilepsy is contagious.¹¹ This leads to PWE experiencing social isolation within the community and/or family. This public fear of “catching epilepsy” leads to people with epilepsy not receiving first aid during a seizure in a public place.

Stigma Mitigation:

Counteracting epilepsy stigma involves addressing misperceptions and improving knowledge of and access to effective treatment. Because stigma is complex, multiple methods are needed. Sensitization, or awareness raising, focuses on addressing community ignorance about epilepsy. A study in Mali noted that fewer than 24% of parents of a child with epilepsy obtained knowledge of epilepsy from a healthcare worker; instead, neighbors and traditional healers were common sources.¹² Community campaigns, school-based programs and media campaigns or interviews are common approaches to introduce the public to basic facts. Key messaging includes “Epilepsy is a medical condition” and “Epilepsy is not contagious”. Some program formats allow participants to have their questions about the condition answered.

Epilepsy education is more targeted and frequently aimed at key groups who encounter PWE in daily activities such as

teachers, health workers or PWE and their households. These trainings seek consistent knowledge application by community leaders and/or help PWE and their families to self-advocate. Peer groups of PWE can also help reduce the impact of stigma.¹³ Group meetings empower PWE through access to epilepsy information, decreased social isolation, problem solving with peers and improved self-image.

Wider access to medical treatment for epilepsy also aids stigma reduction. When PWE know that treatment options are accessible, they are less likely to seek help from traditional healers, a system that perpetuates myths about epilepsy’s mystical origins. In contrast, successful medical treatment provides a community with “living examples” that epilepsy is a medical condition that can be treated.

The role of foundations and NGOs:

Foundations and NGOs can work together to help mitigate the harmful stigma around epilepsy. While there are a variety of stakeholders engaged in epilepsy stigma and care, for simplicity this article focuses on two classifications of organizations, broadly categorized as:

1) Resource organizations, such as foundations that provide funding to epilepsy programs and initiatives. Examples of resource organizations at the global level include International Bureau for Epilepsy (IBE), Epilepsy Alliance of Africa (EAA), ROW Foundation, BAND Foundation, and The Defeating Epilepsy Foundation. Each may provide financial support to organizations directly involved in implementing activities to improve epilepsy care, expand advocacy and/or reduce stigma.

2) Program implementors, such as NGOs focused in whole or in part on epilepsy. These organizations are often patient-focused non-government organizations (NGOs) or community-based organizations (CBOs) that have built knowledge of and relationships in the communities in which they operate. These implementors have first-hand knowledge of community culture and prominent barriers to PWE and are well-positioned to identify effective methods to reach specific audiences, such as school-age children, community leaders, parent groups, medical providers and others. Examples of implementors in Africa include IBE and EAA chapters, as well as numerous independent organizations across the continent.

The role of resource organizations is to identify the implementors that offer the best outcomes using the available resources. The role of the implementors is to design and implement strategies that offer the best outcomes using available resources. Below are three examples of implementors employing a range of methods to reduce epilepsy stigma.

Epilepsy stigma mitigation methodologies:

NERI Clinics, Purple Bench Initiative, and Medical Assistance Sierra Leone are examples of program implementors that employ various stigma mitigation methodologies in their local communities.

NERI CLINICS

Neri Clinics provides accessible health services in Linda township, a peri-urban area near Lusaka, Zambia. A preliminary study of knowledge, attitudes and perceptions of epilepsy conducted at the clinic provides insight into epilepsy stigma in this community by examining the responses of two key groups: community members and epilepsy caregivers through focus group discussions and a questionnaire. The study is part of an epilepsy community health worker (CHW) program de-

ployed to improve pediatric epilepsy care and reduce stigma in a community of 25,000 people.

Focus group discussions with community members included topics such as attitudes toward witnessing a child during a seizure, knowledge of facts about epilepsy and community perceptions of epilepsy. One consensus amongst the group was that speaking about epilepsy in their community was unfavorable. Various comments indicated perceptions that epilepsy is “not a good illness” and that it is related to witchcraft or demons. Some respondents had difficulty explaining why, but they “didn’t feel good about” epilepsy. Participating caregivers had a significant percentage of unanswered questions about the cause of the child’s epilepsy on their questionnaire, illustrating knowledge gaps about the condition. Caregivers reported low rates of school attendance for their children, perhaps an indicator of stigma experienced by students. Both groups had gaps in knowledge about seizure first aid, highlighting a need for community education on the topic.

Plans for community de-stigmatization activities have been delayed due to pandemic restrictions, but plans include epilepsy trainings for community leaders (faith leaders, teachers and others) to promote epilepsy knowledge and the inclusion of children with epilepsy in community life. Meanwhile, trained CHWs continue to provide support to families affected by epilepsy. Children receiving anti-seizure medication through the clinic are reported to have fewer seizures and more families have come forward with children to be evaluated.

PURPLE BENCH INITIATIVE

Purple Bench Initiative (PBI) is an NGO in Masaka, Uganda that engages with community members to improve the lives of PWE, focused on addressing stigma. PBI approaches the problem as a pervasive lack of epilepsy knowledge at all levels of the community. PBI works systematically to demystify epilepsy by creating ‘Epilepsy Smart Communities’ that:

- Are informed of possible causes of epilepsy
- Have knowledge of seizure first aid
- Can answer frequently asked questions about epilepsy
- Promote social acceptance so PWE can live free of stigma and discrimination

PBI’s strategy is to engage with a wide range of stakeholders throughout its target district and villages:

- District government – Targeted workshops for top administration to foster an improved understanding of epilepsy and to gain support for policies that positively impact PWE
 - Village-level councils and community leaders
 - NGOs and CBOs – Collaborate to reduce institutionalized stigma
 - Village Health Teams (VHTs) – Community health worker trainings to identify epilepsy-affected households and provide village-level feedback for follow-up
 - Schools – Activities to facilitate mindset change for the next generation by working with students across all grade levels, both collectively individually
 - Community-at-large – Media appearances by PBI’s founder to answer questions and dispel myths about epilepsy
- PBI focuses on important and understandable lessons that are critical to dispelling myths about epilepsy. For example, community members learning that the saliva of a person having a seizure does not transmit epilepsy can increase the likelihood of that person receiving emergency assistance during a seizure.

In late 2020, PBI experimented with a new approach. PBI identified Susan, a teenage girl with epilepsy who had recently suffered a seizure-related burn injury during a fall onto a cooking fire. Susan was also the victim of ongoing social stigma in her community. PBI designed a set of activities to improve Susan’s safety and quality of life in a visible way to educate the community about epilepsy. PBI recruited community members to dig a rainwater collection tank for household water and to build a safe cookstove to protect Susan from flames and smoke. The volunteers received t-shirts that increased the visibility of the effort. During the week, PBI held an epilepsy awareness session to communicate that epilepsy is a medical condition.

Camaraderie with her community during the project boosted Susan’s self-esteem. Susan was paired with a community health worker who became her mentor, while PBI arranged a hospital visit that led to a new medication regimen that has her seizures under control. The change in Susan’s life and self-perception has been dramatic – she expresses a new confidence and is in school full-time. The result was not limited to one person – the community gained an improved understanding of epilepsy and presumably a reduced likelihood to participate in stigmatizing PWE going forward.

MEDICAL ASSISTANCE SIERRA LEONE

Medical Assistance Sierra Leone (MASL) is a charity based in the United Kingdom that supports access to health care and urgent medical treatment in Sierra Leone. MASL works with a variety of stakeholders to raise awareness around key health issues, including stigma and discrimination against PWE.

MASL’s experience is that much of epilepsy stigma in Sierra Leone is rooted in the belief that seizures are the result of witchcraft or other spiritual forces. Every PWE that MASL has worked with to date has been accused of witchcraft either directly or indirectly. In 2018, MASL commissioned a study led by Ibrahim Bangura that surveyed 25 individuals accused of witchcraft as well as parents accused of witchcraft because of their child’s epilepsy. The findings indicated:

- Family members were frequent initiators of the accusations.
 - The primary source for confirmation of the accusations are traditional and spiritual healers, religious leaders and other community leaders.
 - Family involvement in the accusations leads the majority of PWE (84%) to comply with witchcraft-focused treatment, often out of fear or perceived lack of choice.
- These findings have shaped MASL’s ongoing campaign to promote epilepsy as a medical condition. MASL challenges misconceptions around witchcraft and encourages individuals to seek treatment using a variety of mediums to communicate the message:
- Radio advertisements and “jingles”
 - TV and radio appearances of self-advocates, parents/caregivers and traditional healers who now recognize former treatment methods were ineffective
 - Banners to promote local epilepsy clinics, including access to an epilepsy helpline
 - Leaflets listing clinics for treatment and basic epilepsy information, distributed in schools, places of worship and at community events
 - Community-based awareness sessions involving chiefs and local leaders
 - Training of community health workers to spread accurate

epilepsy messaging.

MASL believes that each conversation, community dialogue and radio advertisement can make a positive difference in addressing stigma. MASL cites a 2018 research study that demonstrated that only 25% of a social group is the tipping point needed to affect social change within that group.¹⁴ MASL believes that the sole voice speaking up, the one person in four, carries significant weight and influence. MASL therefore does not need to change everyone's understanding of epilepsy but seek out informed representatives across all levels of society and in each community.

MASL offers school awareness programs to deliver seizure first aid training, provide information about epilepsy and available support. MASL leaves a laminated poster for the school reception area as a reminder of lessons taught. To reach young students and their families, MASL also recently introduced the Jariatu Has Epilepsy children's book into schools. MASL plans to develop targeted messaging for social media and film for urban-based young people and to explore the use of drama, music and dance to reach communities with health messaging. MASL's awareness-raising efforts and network of epilepsy clinics have contributed to a reduction in the number of people seeking alternative treatment and a reduction in reported witchcraft accusations. Despite this, 33% of patients still seek alternative treatment even after attending clinics and while on a successful medical treatment program.

Conclusion:

NGOs are building upon their community knowledge and relationships to address epilepsy stigma using a variety of methodologies. The best implementors will continue to measure success, survey community needs and adapt their methods. Most implementors' work is constrained by a lack of resources.

Healthcare providers have a role in stigma mitigation through epilepsy treatment. With seizure control, PWE can avoid some stigmas. With a shortage of neurologists in many lower-income countries, especially in rural areas, primary care providers need training on epilepsy management. A commitment to epilepsy treatment by health systems is crucial. Providing diagnostic tools and consistent, affordable medication supplies supports seizure control and stigma reduction simultaneously. Because ongoing financial support is one part of the solution, resource organizations working globally must expand their support of the implementors. Communicating about the consequences of epilepsy stigma in lower-resource regions and engaging more healthcare professionals and epilepsy patient groups in cross-cultural epilepsy efforts are avenues to explore. Millions of people still live with untreated epilepsy and these PWE suffer more from the effects of epilepsy stigma than their treated counterparts. As healthcare providers address the medical needs of PWE, resource organizations and implementors must continue to work in tandem on the urgent matter of eradicating epilepsy stigma in all its forms.

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