



Review

Epilepsy misconceptions and stigma reduction interventions in sub-Saharan Africa, a systematic review



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ABSTRACT

Objective: This systematic review identified papers that described epilepsy misconceptions or stigma in sub-Saharan Africa (SSA) and research interventions focused on reducing these misconceptions.

Materials and methods: Publications in the English language from January 2000 to October 2017 that described original research conducted in SSA on misconceptions about epilepsy were utilized.

Results: Twenty-three publications were identified. Studies were from Nigeria (N = 4), Cameroon (N = 4), Uganda (N = 3), Zambia (N = 2), Ethiopia (N = 2), Tanzania (N = 2), Kenya (N = 2), Ghana, Zimbabwe, Benin, and Mali (N = 1 each). The studies included assessments of misconceptions among healthcare providers and medical students (N = 3), high school students (N = 2), teachers (N = 2), the general public (N = 10), people with epilepsy (N = 7), and traditional healers (N = 1). Only two studies had stigma-focused interventions. Majority of the studies reported limitations to socialization with people with epilepsy and various beliefs associated with epilepsy.

Conclusions: Epilepsy misconceptions, stigmatizing cultural beliefs, and perceptions were widely prevalent in SSA, and there are a few studies targeting epilepsy stigma. Existing stigma-reduction educational approaches may be impractical for general population implementation. Scalable approaches to reduce stigma are urgently needed within SSA.

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1. Introduction

Epilepsy presents various challenges to those affected including the family and care providers. Stigma remains the biggest cause of limitations and discomfort for people with epilepsy and is common in many cultures [1]. Stigma negatively influences the lives of people with epilepsy and their families [2–4]. The Global Campaign Against Epilepsy (GCAE): Out of the Shadows, a joint venture by the World Health Organization, the International League Against Epilepsy, and the International Bureau for Epilepsy, was established in 1997 with a mission of improving acceptability, treatment services, and prevention of epilepsy

worldwide [5]. Despite efforts to increase awareness accurate knowledge of epilepsy in the developing world, there is a dearth of knowledge regarding interventions that can reduce stigma. In high middle-income countries (HMIC), public awareness campaigns have been successfully developed gradually leading to the reduction in the burden of epilepsy stigma [6,7]. These approaches are either under-developed or lacking in most of sub-Saharan Africa (SSA). Interventions aimed at reducing stigma can potentially inform newer strategies to change attitudes and facilitate a supportive, positive, and socially inclusive environment for people with epilepsy in SSA.

To understand recent misconceptions and stigma surrounding epilepsy in SSA in preparation to developing an approach that might modify these misconceptions, we conducted a systematic literature review focusing on research in epilepsy stigma over the last two decades in SSA. The review identified key epilepsy stigma themes in these studies. We were especially interested in research that evaluated epilepsy misconceptions and epilepsy stigma reduction interventions and summarized the stigma reduction interventions delivered.

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2. Materials and methods

Our investigations targeted three foci, all focused on manuscripts published from January 2000 to October 2017 to ensure contemporary relevance: 1) a survey of original reports on epilepsy stigma with emphasis on country or region of the world of origin, 2) focus on original reports that addressed misconceptions and attitudes of the general public (people without epilepsy) towards people with epilepsy in SSA, and 3) a focused assessment of articles presenting interventions specifically designed to reduce epilepsy stigma in SSA.

2.1. Literature review and search strategy

PubMed, World Health Organization (WHO) Africa-African Index Medicus, and EMBASE databases were searched for original research studies and reviews published in English between January 2000 and October 2017. Search terms used were epilepsy*, seizure*, epilepsy misconception*, epilepsy myth*, stigma, bias, restriction* discrimination*, Africa* and sub-Saharan Africa; (*) was used as a wildcard to include several forms of the terms. A second search was done using EMBASE using the following query: (“epilepsy”[MeSH Terms] OR “epilepsy”[All Fields]) AND (“social stigma”[MeSH Terms] OR (“social”[All Fields] AND “stigma”[All Fields]) OR “social stigma”[All Fields] OR “stigma”[All Fields]) AND (“methods”[MeSH Terms] OR “methods”[All Fields] OR “intervention”[All Fields]) AND (“Africa”[MeSH Terms] OR “Africa”[All Fields]).

Another search was done using WHO Africa – African Index Medicus using keywords (epilepsy or seizure*) along with discrimination*, restriction*, myth*, stigma*, Africa* or sub-Saharan Africa as secondary keywords. Results from the search were used to identify records based on the country or region of origin (where the research was conducted) and the type of report (original). Literature regarding health-related quality of life (HRQOL) was included if it addressed epilepsy stigma. Articles that addressed acute seizures secondary to brain injury/trauma, poststroke seizures, pediatric studies, and seizures related to pregnancy (i.e., eclampsia) or medical conditions (i.e., infectious causes) were excluded.

2.2. Literature reflecting sub-Saharan Africa

The search was intended to determine the distribution of research studies on epilepsy myths and misconceptions and included both felt and enacted epilepsy stigma in Africa, as well as focusing on the effect of epilepsy treatments/interventions on stigma reduction among people with epilepsy. Inclusion criteria were as follows: observational or experimental studies on misconceptions about epilepsy among adults in the general population, or subgroups defined by role or occupation (teachers, college students, or health workers, etc.), original research (randomized controlled trials, prospective nonrandomized controlled and uncontrolled interventional studies), publications in English. We also included studies that focused on self-perceived stigma in people with epilepsy. A reference search of reviews on epilepsy stigma from SSA was used to identify additional studies potentially missed in the initial search.

2.3. Interventional studies

In order to inform the planning of future intervention studies, each interventional study was assessed for the specific health communication strategies used to deliver the antistigma messages. Our study team is adopting and developing a culturally acceptable stigma reduction approach that is feasible in SSA settings and targeting adults with epilepsy.

2.4. Selection of publications

All abstracts were prescreened for relevance by one reviewer (MK), based on title and abstract information. Abstracts were then assessed by a three-member review team (MK, MNK, and WB) for inclusion confirmation. Initially, all reviewers evaluated a list of the same abstracts to ensure consistent application of inclusion and exclusion criteria. Discrepancies were discussed until consensus was reached. Once the inclusion and exclusion criteria were finalized, all abstracts were reviewed by two independent reviewers (MK and MNK) to determine suitability for further in-depth review.

2.5. Data collection, synthesis, and reporting

Reviewers used a structured data extraction form modeled on other systematic reviews and recommendation [8–10]. Reports were also assessed to see whether they included the following: 1) an active intervention to reduce epilepsy misconceptions or stigma, 2) a health communication approach, and 3) a focus on adults and youths.

3. Results

3.1. Literature review

3.1.1. Overall description of the African publications

Twenty-three publications met the inclusion criteria (Fig. 1). Publication frequency is fairly uniform across the study period except for the period between 2001 and 2003, when there were no publications from SSA. Most studies were from Nigeria (N = 4), Cameroon (N = 4), Uganda (N = 3), Zambia (N = 2), Ethiopia (N = 2), Tanzania (N = 2), Kenya (N = 2), Ghana, Zimbabwe, Benin, and Mali (N = 1 each). More than half of these studies (13/23) were self-funded, while others were supported by nongovernment organizations (6) and pharmaceutical companies (2). The studies included assessments of misconceptions among healthcare providers and medical students (N = 3), high school students (N = 2), teachers (N = 2), the general public (N = 8), people with epilepsy (N = 6), and traditional healers (N = 1). The studies were highly variable in format, design, and quality. Many of the studies combined assessment of knowledge and attitudes about epilepsy.

3.1.2. Assessments of epilepsy misconceptions

Many of the studies used a structured, closed-ended questionnaire, either published previously by others or created by the authors, to assess epilepsy misconceptions, stigma, and attitudes [11]. A number of the questions asked were based on the questionnaires from international studies while others were based on African studies from Tanzania, Cameroon, Nigeria, Senegal, and Zambia often with some modifications [12–18]. The majority of these studies used cross-sectional face-to-face interviews or self-administered questionnaires. Three studies from Tanzania, Kenya, and Nigeria also utilized focus group discussions to explore knowledge, attitudes, practices, and barriers toward epilepsy within communities or people with epilepsy [19,20]. One study explored the knowledge, perceptions, and practices toward epilepsy among traditional healers [21].

3.1.3. Characterization of epilepsy misconceptions

3.1.3.1. *Epilepsy misconception themes.* Closed-ended instruments used to assess misconceptions tended to reflect beliefs or attitudes that have been previously well-established. Misconceptions (Table 1) fell into several categories: employment, social status/integration, restrictions or limitations, cause/nature of disease, treatment, prognosis, and first aid. There was a relatively high degree of similarity across studies that identified misconceptions, but given the diverse target populations

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