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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: English language publications from January 2000 to October 2017 that described original research conducted in SSA on misconceptions about epilepsy.

Results: Twenty-three publications were identified. Studies were from Nigeria (N=4), Cameroon (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 health care 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 (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 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.

Keywords

Epilepsy; Seizures; Stigma; Misconceptions; Attitudes

Authors' Contribution

All authors critically read through the manuscript and revised the manuscript for important intellectual content. All authors discussed the results and commented on the manuscript. All authors read and approved the final manuscript.

Competing Interests

The authors declare that they have no competing interests.

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 of 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.

Materials and methods

Our investigations targeted three foci, all focused on manuscripts published from 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) toward people with epilepsy in SSA and 3) a focused assessment of articles presenting interventions specifically designed to reduce epilepsy stigma in SSA.

Literature review and search strategy

PubMed, 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 keywords; (“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, post-stroke seizures, pediatric studies, and seizures related to pregnancy (i.e. eclampsia) or medical conditions (i.e. infectious causes) were excluded.

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 treatment/interventions on stigma reduction among people with epilepsy. Inclusion criteria were; 1) observational or experimental studies on misconceptions about epilepsy among adults in the general population, or sub groups defined by role or occupation (teachers, college students or health workers etc.), original research (randomized controlled trials, prospective non randomized 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 were used to identify additional studies potentially missed in the initial search.

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 anti-stigma 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.

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, 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, MNK) to determine suitability for further in-depth review.

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 1) an active intervention to reduce epilepsy misconceptions or stigma, 2) a health communication approach, and 3) a focus on adults and youths.

Results

Literature review

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 – 2003 when there were no publications from SSA. Most studies were from Nigeria (4), Cameroon (4), Uganda (N=3), Zambia (N=2), Ethiopia (N=2), Tanzania (N=2), Kenya (N=2), Ghana, Zimbabwe, Benin and Mali (N=1). More than half of these studies (13/23) were self-funded, while others were supported by non-governmental organizations (6) and pharmaceutical companies (2). The studies included assessments of misconceptions among health care providers and medical students (N=3), high school students (N=2) teachers (N=2), general public (N=8), people with epilepsy (N=6), and traditional healers (1). The studies were highly variable in format, design and quality. Many of the studies combined assessment of knowledge and attitudes about epilepsy.

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 towards epilepsy within communities or people with epilepsy (19, 20). One study explored the knowledge, perceptions and practices towards epilepsy among traditional healers (21).

Characterization of epilepsy misconceptions

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 and methodologies, we could not compare how these misconceptions occurred across various sub groups. A summary of misconceptions and stigma reported by various studies in SSA is shown in Table 2.

Public perception of how epilepsy affects people with epilepsy: A number of studies have reported that study respondents who do not have epilepsy have positive attitudes towards those with epilepsy. They have also reported discrimination and ostracism towards people with epilepsy from communities leading to difficulties at work and relationships. The most common non stigmatizing responses in one study were believing that epilepsy could be controlled and feeling comfortable with social interactions such as allowing one's offspring to play with people with epilepsy (30%). Refusing one's child to marry a people with

epilepsy within SSA countries was high ranging from 33% in Badissa, Cameroon to 82.5% in Ethiopia (22–28). There were differences regarding social isolation even within similar countries like 67% in rural Cameroon (29) to 33% in Badissa, Cameroon (30). While within Nigeria, marriage was out of the question in Ebonyi state (31), while 93.2% of the respondents would marry people with epilepsy. In Kano, Nigeria, 25.5% of the 227 school teachers would object having a person with epilepsy in their class (32). Among medical students, 59% believed epilepsy to be a mental illness(22), while 35.5% reported it's a form of madness or insanity(29). 60.5% of adult residents would refuse their children to play with or get married to people with epilepsy. Among teachers in Zambia, individuals with poorer knowledge were more likely to recommend traditional healers ($p=0.0004$) (33). The perceptions of how epilepsy affects people with epilepsy were significantly associated with rural residence, male sex and lower education attainment in most of the studies reported (22, 25, 26, 29, 30, 34).

In addition, community members also believe that knowing the correct cause of epilepsy, anti-epileptic drugs and special clinics when made available would reduce the associated stigma in communities. The studies indicate that while the communities do not typically voice stigmatizing ideas or thoughts, their reports of observed community behaviors indicate that stigma exists(6).

Perception of epilepsy among traditional healers: One cross-sectional study with face to face interviews on knowledge, perceptions and practice among 102 traditional healers was conducted in Cameroon (21). The majority of the traditional healers in this study had heard about epilepsy and had witnessed seizures. However, 40% would object their children to associate with, 46.1% would object their children marrying people with epilepsy. About 51% linked epilepsy disease to insanity. Though, 61.8% could not offer any treatment for epilepsy, majority were willing to refer people with epilepsy to the hospital for treatment. However, over two-thirds of the traditional healers would carry out a dangerous action like placing a spoon/cloth in the mouth, tying a person down, putting the head in a toilet hole or forcing medicines down the throat (21).

Perception of epilepsy among people with epilepsy: Among people with epilepsy, the majority of the findings from studies in various sub-Saharan African countries were comparable. They all described a biological etiology for epilepsy, as well as birth injury, inheritance, and infections, as causes of epilepsy(19, 20, 35, 36). The majority reported that experiences with traditional healers were not helpful. They describe that modern medicine had a useful role in treating epilepsy (19, 20). However, people with epilepsy had concerns about disclosing their illness, difficulties in getting married, or experienced problems in an ongoing marriage. One study in Nigeria among women with epilepsy reported an impaired relationship with their spouses (37). From the western African countries of Nigeria and Benin, reported concerns of distress were physical distress during the seizure, and physical abuse from members of their household (36, 37). New patients with epilepsy from Northern Uganda who had not experienced any improvement, had widespread beliefs that epilepsy was a result of witchcraft/curse and cannot be controlled (35). While a study from Kenya reported difficulties in understanding the concepts of prophylactic drug regimens to control

the epilepsy and adherence to drugs was known to be problematic when there is rapid decline of symptoms before the completion of the course of drugs. People with epilepsy also reported lack of adequate knowledge and education regarding their epilepsy as well as health workers lacking interest or sensitivity to their condition(19).

Sources of information on epilepsy.: A number of the studies assessed sources of information about epilepsy within communities and people with epilepsy. However, few outlined the sources of information for either the communities or people with epilepsy regarding epilepsy (38). In one study among teachers from Ethiopia, the most common source of information was an acquaintance with people with epilepsy (51.3%), public media (36.9%) and medical doctors (2.3%) (25). Among people with epilepsy in Kenya, information and education were important issues suggested particularly, information about symptoms and causes of epilepsy, advice about safety and further advice for treatment(19). There were no reports on social media within this region.

Variables associated with misconceptions and stigma among communities and people with epilepsy.

There was an overall agreement over sub-Saharan Africa, that low educational attainment, rural residence and male sex were associated with misconceptions, poor knowledge regarding epilepsy and associated stigma (22, 25, 29, 30, 34). Epilepsy stigma was also most likely to occur in individuals with less education, lower socioeconomic status, rural residence, farming as an occupation, no exposure to people with epilepsy, practicing witchcraft, associated health problems and knowing the correct cause of epilepsy(11, 22, 25, 29, 36, 39). Rural people (442.2%) were most likely to have the highest stigma level (11). One study from Benin found that epilepsy stigma did not appear to have any relation to seizure type and frequency (36).

Interventions to reduce epilepsy stigma: Only two studies from SSA (Ethiopia and Ghana) included an intervention. One study in Ethiopia developed an educational comic book on epilepsy-related knowledge, awareness and attitudes among high school students aged 16years and above. The knowledge, attitudes and awareness significantly changed after reading the comic book for majority of the questions assessed (40).

The study in Ghana the intervention included topics on stigma of epilepsy, causes of epilepsy and treatment of epilepsy. Consistent with the pedagogical and clinical settings, interventions relied on communicating health information via lectures to train the target audience of 40 community nurses, psychiatry nurses and physician assistants. These included sharing stories and experiences to further illustrate the topics. These studies however, did not assess whether this additional knowledge or change in attitude translated into a measurable behavioral changes in real world settings. The impact of the training was not assessed after the intervention. Furthermore, how epilepsy stigma was addressed is not consistently obvious in these studies (27).

Discussion.

Findings from this literature review on epilepsy stigma and stigma reduction efforts suggest there is substantial misconceptions, negative attitudes and stigma surrounding epilepsy in SSA. Despite SSA having the highest burden of epilepsy and associated epilepsy stigma, there is very little literature on stigma reduction interventions/strategies in our settings compared to the developed countries.

There is also limited utilization of qualitative methods to elicit new information which could be used to develop innovative stigma reduction programs.

Despite, the observations reported coming from various countries in SSA, they are comparable in various aspects like poor knowledge regarding epilepsy, high levels of stigma, social isolation of people with epilepsy and widespread beliefs regarding epilepsy. The main factors that have been reported to influence issues related to knowledge, attitudes and perceptions in SSA such as rural residence of the study participants, no or lower levels of education attainment and male sex are uniform throughout SSA studies. Overall, studies conducted within urban settings, more educated communities had higher levels epilepsy knowledge and lower levels of stigma within SSA. Findings from studies in Uganda, Kenya, Tanzania from Eastern Africa were comparable to findings from Zambia southern Africa and Nigeria, Benin, Cameroon in western Africa (11, 13, 22, 29, 33, 36).

Key epilepsy misconception themes in the research literature over the last twenty years include restrictions on normal social roles (socializing with people with epilepsy, marriage, children, employment), conditions associated with epilepsy (cognitive and behavioral difficulties), personal characteristics of people with epilepsy (unreliable, dangerous), limitations on selected on activities (driving, sports), and inaccurate beliefs regarding the causes, treatment and prognosis of epilepsy. These misconceptions are widespread and comparable within sub-Saharan Africa. We could not compare the frequency and nature of misconceptions across SSA due to the differences in study designs and methods. The studies reported were conducted in various populations with some in the general communities or general public, specialized groups like teachers, students or health care providers while others were conducted among people with epilepsy. Public perception which involves general public's misconceptions towards epilepsy may be quite different from well-defined subgroups such as teachers and health care providers and particularly epilepsy patients. This therefore limits the comparison of these groups. However, overall health care providers and teachers had good understanding and attitudes towards people with epilepsy (22, 25, 27, 32, 41, 42). This further supports the finding of higher levels of education significantly associated with good attitudes compared to the general public. Though misinformation and social isolation does occur to a certain extent within this highly educated group. These misperceptions need to be identified and corrected especially among health care providers and teachers to allow fair treatment of people with epilepsy.

Most published studies on misconceptions and stigma used standardized instruments that relied on closed-ended questions. Understanding the implications of the questions in contextual aspect is important as some of the currently used questions might jeopardize

employment opportunities for people with epilepsy. Only three studies utilized open ended / qualitative methods that provide an opportunity to further develop focused questions to study stigma and misconceptions (20, 28, 31).

There were only two interventions in this review, hence it is still not clear how best to reduce stigmatizing attitudes towards epilepsy in the general SSA population (27, 40). In one study, the intervention used didactic and fairly labor-intensive approaches that would likely not be practical and scalable for the general population (27). Most importantly, the enduring impact on epilepsy stigma was not assessed in either of the 2 epilepsy stigma intervention reports.

Given the paucity of evidence based stigma reduction interventions in SSA, it may be reasonable to look at the developed countries as to how future research might be operationalized. Studies from HMIC, epilepsy support groups, public awareness groups and government agencies like the CDC that have tested interventions to address epilepsy stigma offer us an opportunity to adopt these interventions. These need to be adopted, tested for culture appropriateness, acceptability and feasibility. In marked contrast to the developed countries, there has been little or no published studies that have tested interventions to address epilepsy stigma in SSA. There is an urgent need to adopt culturally acceptable and feasible interventions already developed for our settings to address the issue of stigma among people with epilepsy.

Limitations

Our literature search focused on studies published in 2000 – 2017. As with any search, we may not have identified all pertinent articles, and our search and review strategy may have introduced some bias. The fact that we only included English-language articles could have missed articles written in other languages. Another limitation is the issue “social desirability bias”, meaning respondents may have provided answers that they felt were socially acceptable, but may not be reflective of true attitudes and perceptions. Another limitation is that we could not compare the frequency and nature of misconceptions across SSA due to the differences in study designs and methods. Finally, there were only a limited number of epilepsy stigma reduction interventions and a very narrow study population of the existing interventions which may limit the approximation of how these interventions might perform in general population studies.

Conclusion

Epilepsy stigma is pervasive in SSA. There are remarkably few published studies within SSA that target epilepsy stigma reduction efforts. New strategies are required to address the stigmatizing beliefs and develop new approaches that address stigma reduction and create positive affective reactions within SSA.

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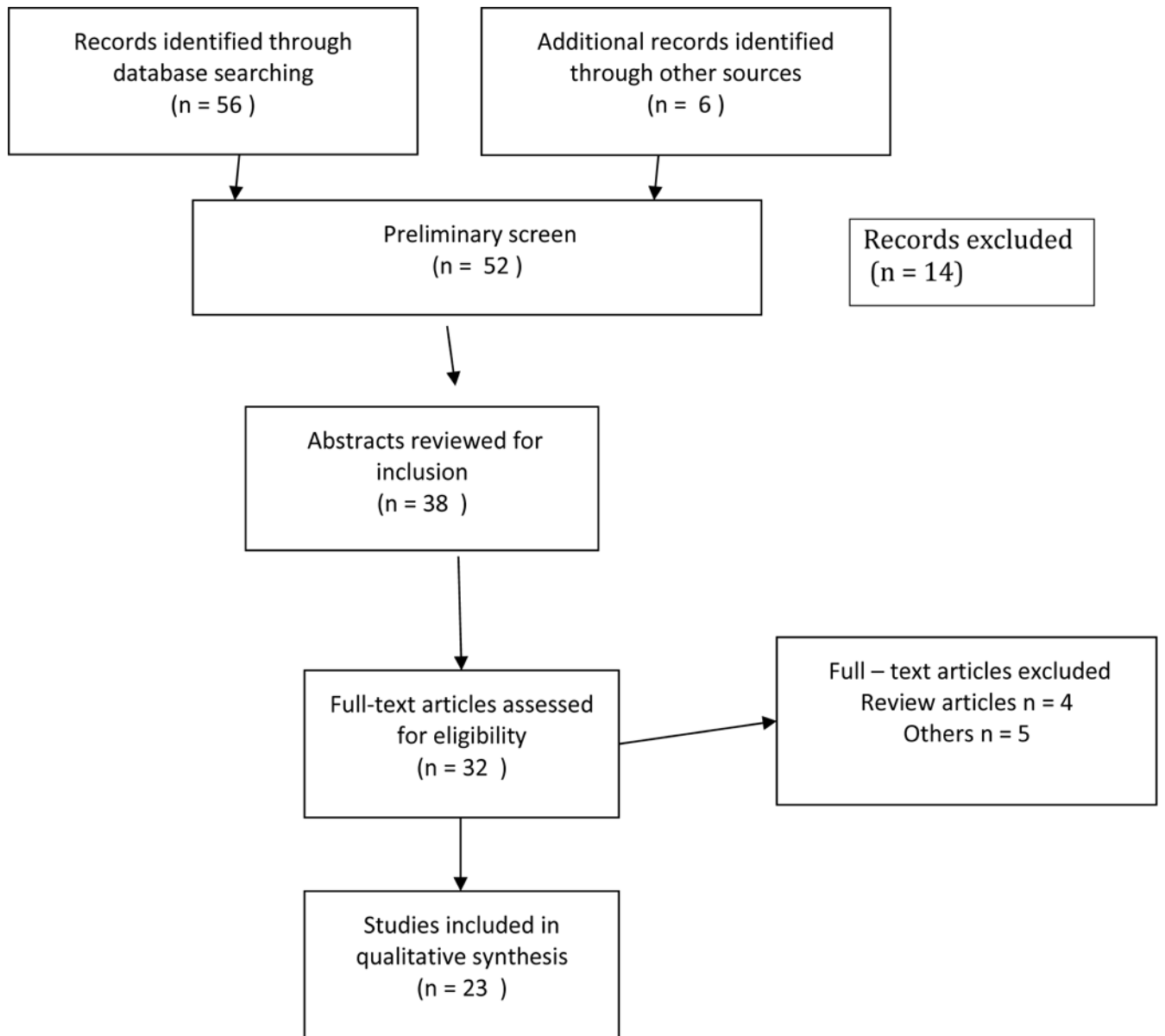


Figure 1:
Literature review flow diagram

Table 1:

Misconception categories identified on studies on epilepsy in SSA

Examples	
Employment	People with epilepsy have insanity Object to employment of people with epilepsy
Restrictions and limitations	Prefer people with epilepsy be in separate classes/schools People with epilepsy cannot participate in sports
Cause and nature of epilepsy	Epilepsy is destiny Is caused by witchcraft Epilepsy is due to demonic possession/evil spirit Epilepsy is a psychiatric disorder Epilepsy is transmitted by saliva Epilepsy is a blood disease (people with epilepsy have weak blood)
Treatment	Should be treated by traditional healers Wearing an amulet Epilepsy is not curable
First aid for seizures	Sacrifice to gods Compliance with cultural taboos Smell the smoke of a struck match Pour water on face of the subject Sprinkled with olive oil Place a spoon between the teeth Give a sweet during a seizure
Integration into community	Objecting to marriage to people with epilepsy people with epilepsy should not play with normal people people with epilepsy can transmit disease (i.e. Epilepsy is contagious)

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Table 2

showing research studies addressing misconceptions or stigma in SSA.

Citation, (year)	Study country	Study population (sample)	Study design	Major finding
Adjei. P, et al (27)	Ghana *	Health care workers (N=40)	Cross-sectional study with stigma training among health care providers.	Epilepsy is perceived to be contagious. Also believed to be due to taboos /spiritual supernatural causes and punishments for social wrongs. Hence treatment with traditional medical theory.
Tekle-Haimanot. R et al, (2016)(40)	Ethiopia *	High school students from rural and urban schools (N=226)	Cross-sectional study with KAP questionnaire among high school students before and after reading a comic book on epilepsy stigma	Comic book about epilepsy changed misconceptions and provided correct information about epilepsy.
Njamnshi. A, et al (2009)(30)	Cameroon	Community door to door survey (N= 164)	Cross-sectional, involving community participants	High levels of awareness following an epilepsy educational and treatment program. Misconceptions occurring with epilepsy reported a form of insanity, contagious and recommend traditional healers.
Bain, L.E et al (2013), (29)	Cameroon	Community survey, (N=520)	Cross-sectional, community survey	Low level of education and bigger family size associated with advocating witchcraft as cause of epilepsy.
Bigelow. J et al, (2015)(22)	Uganda	Medical students (N=96)	Cross-sectional, descriptive study	45% reported that epilepsy is a mental disease. 80% would not allow their children to marry people with epilepsy.
Pupillo. E et al, (2013)(11)	Zambia	Community survey (N=231)	Cross-sectional, rural and urban residents	Poor education and rural residency associated with high levels of stigma
Mbuba. C. K, et al, (2012)(34)	Kenya	Household community survey, (N=673)	Cross-sectional survey for people with epilepsy	people with epilepsy with negative beliefs were less likely to seek biomedical treatment.
Odaga. J. et al, (2008)(35)	Uganda	people with epilepsy records and hospital based study, (N=93)	Retrospective study with a cross-sectional descriptive interview among people with epilepsy	New patients of people with epilepsy who had not experienced any improvement had widespread beliefs that epilepsy was a result of witchcraft/curse and cannot be cured.
Carter. J. A et al, (2012)(19)	Kenya	people with epilepsy and caregivers (N=110)	Cross-sectional, mixed methods study involving, people with epilepsy, family members, community health workers and traditional healers.	Misconceptions about epilepsy derived from superstition about its origin and lack of knowledge about causes, treatment and prognosis contributing to treatment gap.

Citation, (year)	Study country	Study population (sample)	Study design	Major finding
Owalabi. L.F, et al, (2014)(26)	Nigeria	High school teachers (N=200)	Cross-sectional study for knowledge and attitudes	There is a low level of knowledge about epilepsy and misconceptions about epilepsy.
Komolafe. M.A, et al, (2012)(37)	Nigeria	Community survey among women with epilepsy (N=63) and 69 controls	Cross-sectional survey matched for age, social status and site of care.	Women with epilepsy in Nigeria face multiple social and economic challenges. One third face physical abuse from members of their household with 10% reporting rape.
Quereshi. C et al, (2017)(20)	Tanzania	Teachers & parents of people with epilepsy (N=36)	Mixed methods study with cross-sectional and focus group discussion	Barriers to young people with epilepsy's education included parental stigmatization, teacher's inadequate seizure management. Teachers believed that parents with young people with epilepsy believe in spiritual etiology and traditional management.
Rafael. F et al, (2010) (36)	Benin	Community survey (rural) door to door, (N=80)	Mixed methods study with qualitative and Focus group discussion	High prevalence of stigma in Benin. Social factors (social isolation and marital problems) influence stigma.
Ezeala-Adikaibe. B.A et al, (2013) (13)	Nigeria	Urban community dwellers (N=456)	Cross-sectional descriptive study	There is low knowledge among urban dwellers and fraught with misconception and gaps.
Njamnshi A.K et al, (2009)(41)	Cameroon	Health workers (student nurses and laboratory assistants) (N=340)	Cross-sectional study using a self-administered questionnaire.	High levels of knowledge but erroneous beliefs due exist.
Gebrewold. M.A, et al, (2016)(25)	Ethiopia	Teachers (N=845)	Cross-sectional study using a standardized self-administered questionnaire	High percentage of teachers considered epilepsy a psychiatric illness linked to insanity. Holy water treatment and church healing sessions are remedies. Evil spirit and insanity treatment better by religious methods.
Osungbade K.O, et al, (2011)(28)	Nigeria	Rural community survey (N=365)	Cross-sectional study	Epilepsy poorly understood with incorrect local perceptions and cultural beliefs
Njamnshi A.K, et al, (2010) (21)	Cameroon	Community survey for traditional healers (N=102)	Cross-sectional descriptive study among traditional healers.	Traditional healers well acquainted with epilepsy still have some negative practices.

*-Intervention studies in SSA.