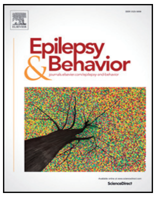

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Review

Stigma reduction interventions for epilepsy: A systematized literature review

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ABSTRACT

Objective: Epilepsy is a disease that is stigmatized globally. Several studies have introduced sensitization efforts to reduce stigma towards people with epilepsy (PWE) in various settings. Although sensitization efforts have shown some evidence of improved attitudes towards epilepsy, progress has been limited. This systematized literature review summarizes the existing literature concerning interventions that reduce stigma towards PWE. By conducting an overview of existing interventions, we aimed to consolidate knowledge and outcomes of existing efforts as well as highlight gaps and directions for future interventions.
Methods: We searched MEDLINE (via PubMed) and Embase for English-language studies published between January 1, 1970 and November 15, 2017 that focused on stigma reduction strategies for PWE in any global setting. Studies were included if they described a stigma reduction intervention for epilepsy. Studies were excluded if they were reviews, editorials, conference proceedings, abstracts, or did not discuss a stigma reduction intervention. We thematically grouped studies based on type(s) of intervention(s) addressed and summarized interventions, outcome measures, and results for each study included in the review.
Results: Of the 1975 initial citations, 32 studies met our inclusion criteria. Interventions clustered into four broad categories including public awareness interventions, policy-based interventions, school-based interventions, and interventions that targeted PWE themselves as well as their caregivers and peers. Efficacy of these interventions as reported by the authors was mixed. Many studies did not use validated outcome measures to assess stigma.
Conclusions: Although intervention efforts have been made towards epilepsy stigma reduction at many levels, stigma towards and discrimination against PWE prevail worldwide. About 75% of the studies included in this review were conducted in high-income countries (HICs) despite the disproportional need in low- and middle-income countries (LMICs). Furthermore, robust outcome measures to assess efficacy in stigma reduction for interventions are lacking, calling into question the validity of reported outcomes for both positive and null findings. Therefore, more work is needed in both developing effective stigma reduction strategies, especially in LMICs, and validating tools to measure their efficacy.
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1. Introduction

Epilepsy is a chronic neurological disease that is characterized by recurrent seizures caused by abnormal electrical activity in the brain. About 70 million people have epilepsy globally [1], and 80% of people with epilepsy (PWE) live in low- and middle-income countries (LMICs), where access to treatment is poor [2].

Because of various myths about the neurological condition in communities worldwide, stigma accompanies the experience of epilepsy among individuals affected [3,4]. This stigma impacts the lives of PWE to a profound extent. Historically, epilepsy has been conceptualized as being caused by demonic possessions, witchcraft, and divine punishment [5,6]. These conceptualizations persist today and can not only lead to harmful social effects for PWE and their families, but also influence care-seeking behaviors and treatment compliance. Although the extent of stigma and discrimination faced by PWE varies by location, these social effects contribute substantially to epilepsy morbidity and can be more debilitating than the seizures themselves [5,6]. Stigma can also impede care-seeking [7], thus contributing to the perpetuation of the illness.

Recognizing the growing burden of epilepsy, the World Health Organization (WHO), International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE) formed the 'Out of the Shadows' - Global Campaign Against Epilepsy in 1997 with the aim of improving the acceptability of the illness, increasing access to treatment, and enhancing treatment services, as well as improving prevention efforts globally [8]. In 2015, the World Health Assembly approved the WHO Resolution on the Global Burden of Epilepsy, which has facilitated efforts to address gaps in treatment and awareness of epilepsy [9]. With the improvement of treatment provision and various stigma reduction efforts around the world, many negative attitudes towards PWE have diminished [5,8]. Yet, stigma remains pervasive enough to impact PWE in social, community, workplace, and educational settings [5,8,10]. For example, in Sub-Saharan Africa (SSA), which experiences a high epilepsy disease burden and where misconceptions about it are highly prevalent, few stigma-reduction interventions have been studied [11]. There is a great need to develop effective stigma reduction interventions targeting the general public as well as PWE and their caregivers.

The purpose of this systematized literature review was to summarize the existing interventions that aim to reduce stigma in PWE globally, and to bring these findings into the context of efforts to mitigate epilepsy-related stigma in Uganda. By consolidating existing efforts in epilepsy stigma reduction, we hope to highlight future directions of research that can contribute to the development and implementation of effective interventions.

2. Methods

2.1. Literature search strategy

Fig. 1 illustrates the literature search strategy used. MEDLINE (via PubMed) and Embase databases were searched using subject headings and keywords related to "epilepsy" and "stigma." The search was kept broad in order to be inclusive of all studies that used an intervention targeted at stigma reduction. References were imported into Endnote. After duplicates were removed, the initial searches yielded 1975 citations. Two independent reviewers (PC and NAS) screened titles and abstracts of all studies for initial relevance. From this, 64 full-text studies were assessed for eligibility by the same reviewers. Studies were included in this review if they were written in English, published between January 1, 1970 and November 15, 2017, and described a stigma reduction intervention for epilepsy. Studies were not included if they were reviews, editorials, conference proceedings, abstracts, or did not discuss a stigma reduction intervention. Gray literature was not included in the search.

Thirty-two studies met inclusion criteria. Both interviewers independently extracted information from each of these studies. The reviewers met after the screening, eligibility, and extraction phases to discuss and resolve any discrepancies at each stage.

2.2. Summarization of articles included in the literature review

We grouped articles by the types of interventions they described. We also summarized the location of the study, the intervention that was evaluated, outcome measures and whether the measures were validated, and efficacy reported by the authors for each study. To evaluate whether outcome measures were validated prior to use, we looked within the citations of each article.

3. Results

Among selected articles, there were four main types of interventions: general public awareness, policy-based, school-based, and patient-based interventions. Common strategies for each intervention type are summarized in Table 1. The studies included in this review were from both high-income countries (HICs) and LMICs: USA, UK, Korea, Australia, Croatia, Japan, Italy, Saudi Arabia, Canada, Czech Republic, India, Nigeria, Austria, Ethiopia, Germany, Zambia, and Kenya. Out of the 32 studies, 24 were conducted in HICs and eight were conducted in LMICs. A summary of all interventions as well as their outcome measures and effectiveness in stigma reduction is summarized in Table 2.

3.1. Public awareness interventions

Public awareness interventions have utilized a variety of strategies and vary with regard to scope. Interventions have included nationwide, city-wide, and village-wide public education campaigns with a diverse range of activities, such as lectures, distribution of pamphlets, entertainment events, public service announcements, and utilization of the media [12–20]. Strategies that have utilized informational videos include media coverage of car accidents involving PWE [15,18,20], first aid responses to manage seizure episodes directed at the public [13], and competency and social inclusion in PWE [21]. The common theme among all of these intervention strategies is that greater knowledge about epilepsy should reduce stigma associated with the disease.

3.2. Policy-based interventions

One policy analysis of the implications of a national antidiscrimination law on PWE in the UK was yielded in the search [22]. Government-level policy interventions around the world have instituted antidiscrimination policies that make overt discrimination against PWE unlawful [23,24]. However, despite the existence of such legislation, there are several challenges in implementation of laws, and thus, subtle forms of discrimination are likely to exist in practice [22]. Stigma reduction efforts in employment have also targeted PWE in development of impression management tactics to increase employer favorability in hiring [25], as well as employers in changing attitudes towards PWE [26], with the goal of reducing discrimination in hiring decisions involving PWE.

3.3. School-based interventions

School-based interventions have focused on educating teachers and students, mainly through educational lessons, videos, and storytelling methods such as plays and comic books. Teacher education has focused mainly on knowledge and management of seizures [27–31]. These interventions have sought to equip school teachers with the knowledge and skills to intervene during seizure episodes among students with epilepsy. This increase in knowledge has been projected to not only

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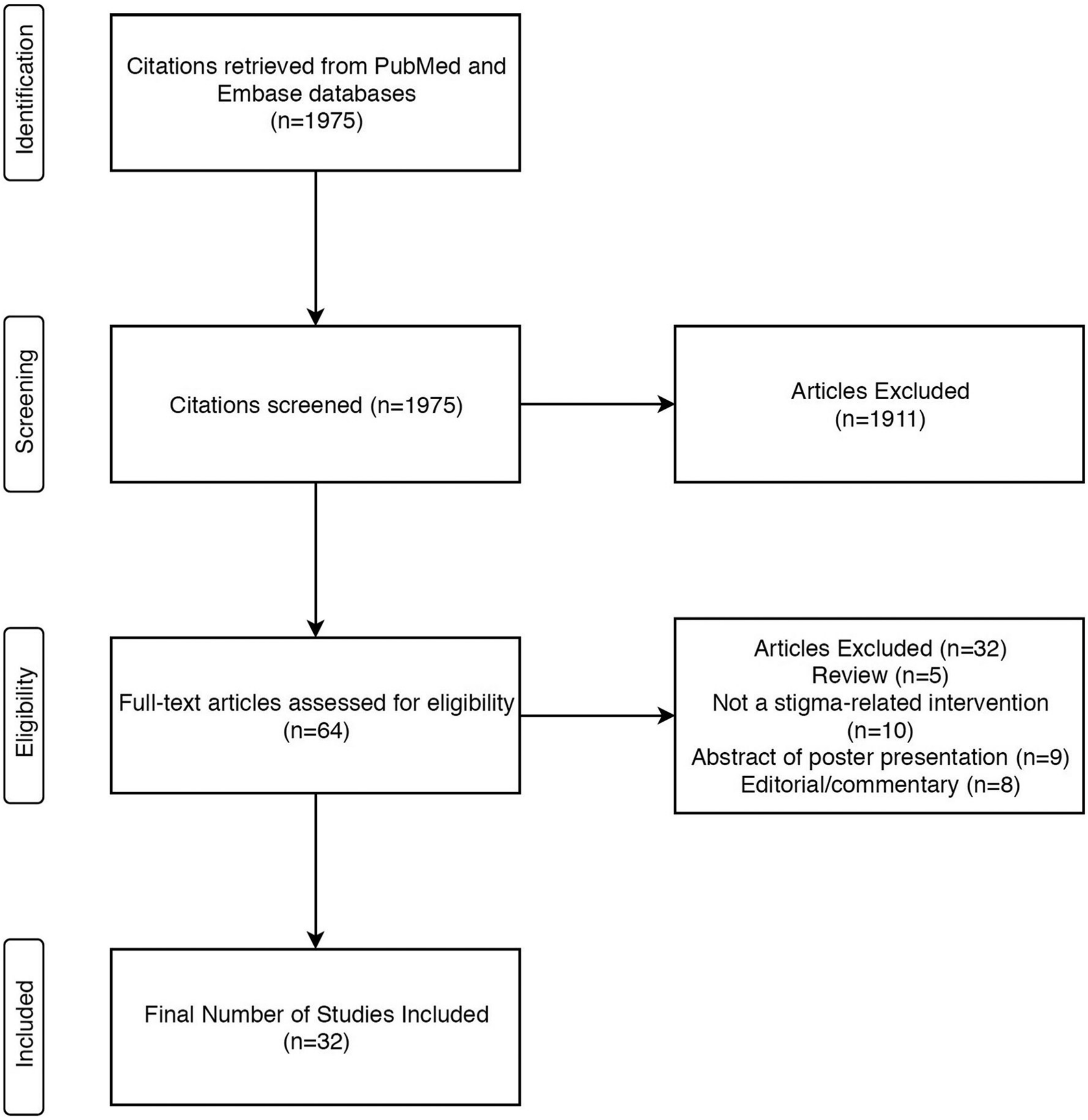

Fig. 1. Flow diagram of articles included in the study.

Table 1
Intervention types and strategies.

Type of intervention	Strategy
General public awareness interventions	Advertisements Public service announcements Pamphlet distribution Lectures Entertainment Web-delivered materials Labels
Policy-based interventions	Antidiscrimination policies Employer-based intervention for hireability
School-based interventions	Teacher education for knowledge of epilepsy and management of seizure episodes Student education through lessons, videos, plays, stories, comics
Patient-based interventions	Coping Self-esteem Self-management Internalized stigma Peer support Family support

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Table 2
Summary of studies included in review.

Study	Location	Intervention description	Outcome measures & validation status of measures	Efficacy
General public awareness interventions				
Kim et al., 2003	Rural Korea	Lectures and small group discussions on knowledge and attitudes of epilepsy at village level	Pre- and postintervention knowledge and attitudes questionnaire; validation study of questionnaire not found	No evidence for change in attitudes after intervention
Roberts & Farhana, 2010	Australia	First-aid information video tested in college students	Pre- and postintervention familiarity and attitude questionnaires; questionnaire was used previously in other studies, but validation of study questionnaire not found	The intervention enhanced knowledge and attitude towards epilepsy
Bielen et al., 2012	Croatia	"Out of the Shadows" campaign activities between 2002 and 2010	Pre- and postintervention questionnaire concerning students' attitudes and knowledge; questionnaire was used previously in other studies, but validation of study questionnaire not found	More positive attitudes after intervention for some constructs only
Okumura et al., 2013	Japan	Media coverage of car accidents involving PWE	Between-group analysis of knowledge and attitude survey between those more exposed to media coverage and those less exposed; questionnaire was used in a previous study, but validation of study questionnaire not found	More positive attitudes and better knowledge in students after media coverage
Mecarelli et al., 2014	Italy	Nationwide campaign including pamphlets, entertainment events, educational movies etc.	Pre- and postintervention knowledge and attitudes about epilepsy in primary school teachers; validation study of questionnaire not found	Knowledge and attitudes improved in some domains.
Alaqeel et al., 2015	Saudi Arabia	City-wide epilepsy awareness campaign in Riyadh	Pre- and postintervention knowledge and attitudes questionnaire; questionnaire was used previously in other studies, but validation of study questionnaire not found	Significant improvement in knowledge and attitudes
Okumura et al., 2015	Japan	Decrease of media coverage of car accidents involving PWE (continuation of study from Okumura et al., 2013)	Between-group analysis of attitudes and knowledge questionnaire, before, during, and after a decrease in media coverage; questionnaire was used in a previous study, but validation of study questionnaire not found	Sustained improvement in positive attitudes and knowledge even after the decrease in media coverage
Price et al., 2015	USA	Yearly Epilepsy Foundation Public Awareness Campaigns from 2001 and 2013	N/A	Not evaluated
Noble & Marson, 2016	UK	Use of the term "PWE" instead of "epileptic" in the English language	Between-group comparison of attitudes using a questionnaire; validation study of questionnaire not found	No evidence that changing terms changed attitudes
Okumura et al., 2016	Japan	Media coverage of car accidents involving PWE (continuation of study from Okumura et al., 2013 and Okumura et al., 2015)	Between-group analysis of attitudes and knowledge questionnaire, before, during, and after a decrease in media coverage; questionnaire was used in a previous study, but validation of study questionnaire not found	Decrease in positive attitudes following media coverage
Sajatovic et al., 2017	USA	Two web-delivered epilepsy stigma reduction videos highlighting competency and social inclusion of PWE	RCT design with Epilepsy Knowledge Questionnaire and Attitudes and Beliefs about Living with Epilepsy questionnaire; used validated questionnaires	No evidence for better attitudes due to intervention
Policy-based interventions				
Sands & Zalkind, 1972	USA	Educational intervention for employers	Pre- and postintervention attitude questionnaire; validation study of questionnaire not found	Intervention did not change employers attitudes about hiring PWE
Delany & Moody, 1999	UK	Disability Discrimination Act 1995 on hiring PWE	Descriptive policy analysis, effectiveness was not assessed empirically	Made overt discrimination illegal, but subtle forms of discrimination still exist
Sung et al., 2017	USA	Impression management tactics to increase employer favorability for hiring	Between-group comparisons of stigma (social dominance orientation scale), general impression (semantic differential scale), and hireability (applicant qualification scale); validation studies for all measures were cited and Cronbach's α values were reported	No evidence for change in stigma between conditions, but intervention increased hireability
School-based interventions				
Rassel et al., 1981	USA	Workshop for public school staff	Pre- and postintervention knowledge and attitudes questionnaire; content validity evaluated prior to use	Statistically significant increase in knowledge and nonsignificant improvement in attitudes
Martiniuk et al., 2007	Canada	30-Minute Thinking about Epilepsy educational program in Grade 5 students	Pre- and postintervention of knowledge and attitudes (33-item questionnaire); questionnaire was validated prior to use	Significant increase in knowledge and attitudes
Martiniuk et al., 2010	Canada	TV PSA showing first aid for a seizure	Pre- and postintervention (1 month after) Thinking about Epilepsy questionnaire; questionnaire was validated prior to use	Those who saw PSA had more positive attitudes about epilepsy
Brabcova et al., 2013	Czech Republic	Two interventions were tested: (1) educational animated video and (2) educational drama	Pre- and postintervention knowledge and stigma questionnaires; content validity evaluated prior to use	Both interventions resulted in better knowledge and attitudes
Goel et al., 2014	India	Teacher education on epilepsy knowledge and first-aid management	Pre- and postintervention knowledge, attitudes, and skill; validation study of questionnaire not found	Significant improvement on most attitude domains after intervention
Eze et al., 2015	Nigeria	Epilepsy lecture for teacher trainees	Pre- and postintervention knowledge, attitudes, and skill; questionnaire adapted from another study, but validation not found	Significant improvement on most attitude domains after intervention

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Table 2 (*continued*)

Study	Location	Intervention description	Outcome measures & validation status of measures	Efficacy
Mecarelli et al., 2015	Italy	Focused training program for primary school teachers on epilepsy knowledge and management	Pre- and postintervention knowledge and attitudes questionnaire; validation study of questionnaire not found	Did not decrease negative attitudes significantly
Kolar et al., 2016	India	Health education targeting epilepsy awareness among school children	Pre- and postintervention knowledge, attitude, and practices about epilepsy; content validity evaluated prior to use	Knowledge, attitudes, and practices increased significantly after intervention
Simon et al., 2016	Austria	Three-lesson education for high school students	Pre- and postintervention knowledge and attitudes questionnaire; validation study of questionnaire not found	Significant increase in knowledge and attitudes
Tekle-Haimanot et al., 2016	Ethiopia	Educational comic book for school children	Pre- and postintervention knowledge, attitudes, practices questionnaire; questionnaire was used previously in other studies, but validation of study questionnaire not found	Significant increase in knowledge and attitudes in some domains
Brabcova et al., 2017	Czech Republic	Educational video and story for fifth grade students	Pre- and postintervention (2 timepoints) stigma scale of epilepsy questionnaire; adapted from a validated scale developed in Brazil, and validation in study context was assessed prior to use	Both interventions had long-term decrease of epilepsy stigma
Dumeier et al., 2017	Germany	Preschool teacher education for management of epilepsy	Pre- and postintervention on knowledge and practices; content validity was evaluated, and the questionnaire was pretested in the target population prior to use	Significant changes in knowledge and practices in some domains
Ezeala-Adikaibe et al., 2013	Nigeria	Epilepsy awareness lecture for secondary school students	Cross-sectional knowledge and attitudes survey of students who attended an epilepsy awareness lecture; authors assessed reliability using Kuder–Richardson Formula 20 and Cronbach's α, but assessment of validity was not found	This was a cross-sectional study so the effect of the intervention cannot be determined; however, authors reported negative knowledge of and attitudes towards epilepsy in the sample
Patient-based interventions				
Snead et al., 2004	USA	Structured psychoeducational group intervention targeting adolescents with epilepsy and their parents	Pre- and postintervention QOLIE-AD-48, Childhood Depression Inventory (CDI), and Revised Children's Manifest Anxiety Scale; all questionnaires used are validated	Overall positive trend for some subscales of QOLIE-AD-48. No improvement on CDI, or Manifest Anxiety Scale
Frizzell et al., 2011	Australia	Personalized epilepsy education targeting knowledge and attitudes of epilepsy, self-esteem, and seizure self-efficacy in adolescents	Pre- and postintervention child attitude towards illness and self-esteem; all questionnaires used are validated	Attitudes towards illness and self-esteem improved significantly
Elafros et al., 2013	Zambia	One-year long peer support group	Pre- and postintervention internalized stigma using 3-item tool; adapted from a questionnaire used in the UK but validation study in study context was not found	Internalized stigma reduced significantly in youth, but not adults
Ibinda et al., 2014	Kenya	Education intervention for patients and their caregivers	Pre- and postintervention beliefs and attitudes score; validation study conducted prior to use	Beliefs and attitudes score improved significantly
Noble et al., 2014	UK	Nurse-led self-management intervention for adult patients with epilepsy seeking care in the emergency department	Number of ED visits, patient well-being (epilepsy-specific quality of life (QoL), seizure frequency, medication management skills, psychological distress, felt stigma, confidence in managing epilepsy, and epilepsy knowledge), and cost-effectiveness at baseline and 6 and 12 months after baseline; patient well-being and cost-effectiveness measures were validated	No significant effect on any outcome except time spent in inpatient care, thus reducing healthcare cost

enhance the safety of PWE in school settings but also reduce stigma for epilepsy by providing basic clinical knowledge to teachers. Furthermore, as educators of the youth, greater knowledge and attitudes in teachers could thus be transferred to children, and negative attitudes towards epilepsy of peers can be discouraged.

Interventions targeting students in school settings used a variety of educational methods, including information about first aid management of seizures, animated videos, plays, stories, comic books, and educational lessons [32–39].

3.4. Patient-based interventions

Interventions focused on individuals with epilepsy have involved psychosocial interventions to reduce internalized stigma and improve coping, self-esteem, and management of seizures [40–44]. Some of these interventions also include psychoeducational interventions for caregivers [40,43] and peers [42].

Two of these interventions focused specifically on knowledge and psychosocial well-being in adolescents [37,38]. One study evaluated a psychoeducational group program that consisted of five key topics: medical knowledge of epilepsy, lifestyle behaviors, family and peer relationships, self-image and self-esteem, and management of stress [40]. This intervention included weekly group sessions with adolescents from ages 13 to 17 years of age and separate but concurrent group sessions with their parents. The other study utilized two two-hour psychoeducational sessions for adolescents from ages 12 to 19 years of age [41]. The first session was at the individual-level, focusing on medical knowledge and treatment. The second session was at the group-level, focusing on lifestyle, coping, safety, employment, and other topics.

One intervention focused specifically on adults seeking care for established epilepsy in emergency departments in the UK [44]. The intervention consisted of two nurse-led sessions, which focused on knowledge of epilepsy and management of the patients own epilepsy (e.g., importance of medication adherence, seizure first aid, awareness of triggers, and risk minimization), including appropriate emergency department use. The sessions were individually tailored to patients, so the sessions varied based on patients' needs.

Of the two studies that included PWE of all ages, one study involved a one-day education program for PWE and their caregivers involving a variety of topics, such as knowledge of epilepsy, drug safety, and what to do before and after a seizure [43]. The education program was delivered using role-play, visuals, group discussions, songs, and narratives

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from PWE. The researchers also expanded their educational program to traditional healers and medical providers (nurses and clinical officers) in order to increase awareness of epilepsy to others engaged in the care of PWE as well as encourage utilization of medical services for patients with epilepsy. The second study involved peer support groups facilitated by a psychiatric clinical officer, a ward support staff member with experience in epilepsy, and an epilepsy clinic administrator, focusing on topics related to disease-related stigma adapted from a human immunodeficiency virus (HIV) stigma toolkit [39]. Participants discussed problem-solving and coping strategies as well as social and medical challenges.

3.5. Efficacy and outcome measures

To measure efficacy of intervention, all studies used questionnaires to assess knowledge and attitudes with the exception of two interventions in which efficacy was not assessed [19,22]. Some studies used more indirect measures of stigma, such as hireability (the employers' perceptions of the qualifications of PWE seeking employment), quality of life, depression, and anxiety [25,40]. Most studies administered these questionnaires before and after the intervention, apart from a few studies [15,18,20,21,44,45] that used between-group comparisons of people who received the interventions and people who did not (Table 2). Only a few studies seemed to use scales that were previously validated to evaluate the interventions used [21,25,30–36,38,40,41,43,44], in which only some examined content validity [30,31,34,35], while the others had previously published literature on psychometric properties.

Overall, interventions in all three groups showed mixed results. Some authors reported positive results, for instance, in the form of enhanced knowledge, attitude change, reduced epilepsy stigma, enhanced self-esteem, and change in practices. On the other hand, some reported positive results in some domains of attitudes, and some showed no evidence for change in attitudes (Table 2) in all four categories of interventions.

4. Discussion

The interventions presented in this review show promising approaches for reducing stigma related to epilepsy. Together, they address comprehensive approaches to address stigma: interventions that target stigma from the public, school-based approaches that can address stigma in younger generations, and interventions tailored to PWE as well as their caregivers and peers to reduce internalized stigma and promote psychosocial support. Although outcomes varied across studies, overall, these efforts show many positive results and have important implications for policy and practice.

However, despite the progress made through these interventions, stigma related to epilepsy prevails globally, adding substantially to the morbidity of epilepsy. Morbidity is especially high in LMICs, where many PWE do not receive adequate treatment. For instance, depression is the most common disorders among PWE [46], and stigma is among the major factors contributing to this comorbidity in SSA [47,48]. Furthermore, epilepsy-related stigma is associated with lower self-efficacy surrounding treatment engagement and lower medication adherence [49]. Stigmatizing policies such as driving and employment restrictions towards PWE may be disproportionate to illness severity [5] and ultimately undermines the quality of life of PWE [50].

Because stigma remains a pervasive and prevailing phenomenon globally, intervention efforts must continue. Various misconceptions regarding the cause of epilepsy, the high epilepsy-related morbidity, high epilepsy treatment gap [51], and limited epilepsy stigma reduction interventions call for a more concerted effort to develop low cost-effective interventions to eliminate stigma related to epilepsy in SSA, and especially Uganda. Our review found fewer studies of epilepsy stigma reduction interventions in SSA (about a third of the studies), which suffers the highest brunt of epilepsy worldwide. No interventions addressing stigma have been conducted and published in Uganda yet. With majority of the epilepsy-associated stigma reduction interventions coming from HICs, it is worthwhile to adopt and assess acceptability for various intervention models in LMICs, more broadly, but especially in SSA, which bears a particularly high epilepsy burden. The lack of literature of intervention models in LMICs may reflect limited resources in these areas to address epilepsy-related stigma compared with HICs. This further highlights the need for global health initiatives to prioritize efforts in the countries with the highest need.

One major challenge for researchers who seek to design and evaluate stigma reduction interventions is the lack of robust outcome measures to assess changes in attitudes and stigma. Many of the studies in this review did not use validated questionnaires. This raises concerns about construct validity in the results reported in the studies.

In addition to the need for robust outcome measures, identification of key intervention targets for inclusion across studies would facilitate direct comparisons of intervention approaches. We note that these targets must be based on qualitative and quantitative assessments of the dynamics facilitating stigma in each respective region, where the drivers of stigma may vary. Whereas misconceptions and misperceptions regarding epilepsy still occur within communities and various groups within Uganda, addressing them is critical in addressing stigma through targeted culturally appropriate information. Ideally, multicomponent interventions would be utilized and include the following: 1) provision of support to overcome both experienced stigma and internalized stigma for PWE and 2) outreach to community leaders and members to shift harmful norms about epilepsy through community dialogs, as well as engagement of local leaders to share antistigma messages. Likewise, advocacy with epilepsy support groups like the Purple Bench [52] and Epilepsy Support Association Uganda [53], two epilepsy support organizations in Uganda, policymakers and community leaders can come together to address epilepsy-associated stigma.

Therefore, there is a need to develop not only outcome measures but also a consensus in the epilepsy research community on gold standard targets of interventions and methods to evaluate them across intervention efforts. For example, school-based interventions could report school attendance as an indirect measure and validated stigma scales as direct measures. One example of a validated scale is the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale developed by the United States Center for Disease Control [54]; this scale will need to be re-evaluated if adapted for use in a different cultural context. Development of robust and consistent measures (yet, relevant for the cultural context) will enhance validity of the measurement of stigma and allow comparability of interventions, allowing researchers to streamline the development of effective intervention strategies or programs, and facilitate efficient allocation of resources towards epilepsy stigma reduction.

A limitation of this review is that non-English publications were excluded, which might have further limited the results. It is possible that articles written in other languages addressed stigma towards epilepsy; however, only a few studies were excluded for this reason. Therefore, this review still provides a comprehensive list of the various types of interventions targeted at stigma reduction in the MEDLINE and Embase databases.

Another limitation of this review is that the search only targeted journal articles and not gray literature. Therefore, interventions, such as educational pamphlets distributed in clinics or in communities, educational efforts transmitted through the media, antidiscrimination policies that have implications for epilepsy, and WHO/ILAE/IBE initiatives that were unpublished in journals were not included. A deeper investigation of epilepsy stigma reduction efforts conducted by religious institutions, community leaders, Ministry of Health activities, and Nongovernmental Organization programs would strengthen the knowledge base on both successful and unsuccessful intervention strategies.

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5. Conclusion

Overall, this review presents an overview of the existing literature of stigma reduction strategies for epilepsy and highlights lack of interventions addressing epilepsy associated stigma in SSA, particularly in Uganda. Although these intervention strategies have been explored and evaluated in various levels, from mass public awareness to individually tailored education, epilepsy-related stigma still contributes substantially to the burden of epilepsy for PWE in SSA. Furthermore, lack of robust outcome measures to assess stigma creates challenges in evaluating and comparing the effectiveness of interventions and point to the need for uniformly utilized, validated measures. Finally, the paucity of intervention studies to reduce stigma relative to its pervasiveness indicate the urgent need for more research, policy, and action, especially in SSA.

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Declaration of competing interest

None.

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