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SPECIAL REPORT

Systematic review of frequency of felt and enacted stigma in epilepsy and determining factors and attitudes toward persons living with epilepsy—Report from the International League Against Epilepsy Task Force on Stigma in Epilepsy

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This article is dedicated to our dear colleague Hanneke de Boer (1946-2015), one of the greatest advocates for people with epilepsy around the world, whose aim was to improve their quality of life and who fought against stigma and negative attitudes.

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Abstract

Objective: To review the evidence of felt and enacted stigma and attitudes toward persons living with epilepsy, and their determining factors.

Methods: Thirteen databases were searched (1985–2019). Abstracts were reviewed in duplicate and data were independently extracted using a standardized form. Studies were characterized using descriptive analysis by whether they addressed "felt" or "enacted" stigma and "attitudes" toward persons living with epilepsy.

Results: Of 4234 abstracts, 132 met eligibility criteria and addressed either felt or enacted stigma and 210 attitudes toward epilepsy. Stigma frequency ranged broadly between regions. Factors associated with enacted stigma included low level of knowledge about epilepsy, lower educational level, lower socioeconomic status, rural areas living, and religious grouping. Negative stereotypes were often internalized by persons with epilepsy, who saw themselves as having an "undesirable difference" and so anticipated being treated differently. Felt stigma was associated with increased risk of psychological difficulties and impaired quality of life. Felt stigma was linked to higher seizure frequency, recency of seizures, younger age at epilepsy onset or longer duration, lower educational level, poorer knowledge about epilepsy, and younger age. An important finding was the potential contribution of epilepsy terminology to the production of stigma. Negative attitudes toward those with epilepsy were described in 100% of included studies, and originated in any population group (students, teachers, healthcare professionals, general public, and those living with epilepsy). Better attitudes were generally noted in those of younger age or higher educational status.

Significance: Whatever the specific beliefs about epilepsy, implications for felt and enacted stigma show considerable commonality worldwide. Although some studies show improvement in attitudes toward those living with epilepsy over time, much work remains to be done to improve attitudes and understand the true occurrence of discrimination against persons with epilepsy.

KEYWORDS
enacted stigma, epilepsy terminology, felt stigma, negative attitudes, negative stereotypes

1 | INTRODUCTION

The issue of stigma has long been a concern of persons with epilepsy and their caregivers and is frequently cited as an important and potentially addressable contributor to impaired quality of life. Despite significant progress in our understanding of the causes of epilepsy, and the remarkable achievements that have been made to prevent and treat it, persons of all ages living with a diagnosis of epilepsy continue to be affected by discrimination and negative attitudes.[1,2]

Any discussion of stigma must start with Goffman's definition of it as "an attribute that is deeply discrediting."[3] Furthermore, Goffman described stigma as stemming from a conceptualization by society constituting of what represents being different and the resultant application of rules and regulations against the person so labeled. Epilepsy stigma can be conceptualized as both "felt" and "enacted."[4] Stigma can be felt both by the person with epilepsy, and by their close associates who fear they will be subject to a process of "courtesy stigma."[3] Felt stigma may involve both anticipating the negative views of others[5]; and as internalizing these and coming to self-stigmatize. Enacted stigma describes actual episodes of discrimination against persons with epilepsy merely on the grounds of their condition. Felt stigma may thus cause as much or more personal anguish and greater quality-of-life reductions than enacted stigma.[4] Prevalence of felt stigma is somewhat easier to assess than that of enacted stigma, since the "enactors" may not recognize or acknowledge that they are doing so. In addition, it may be difficult for people with epilepsy to know whether the behaviors of others are actually discriminatory.

Attitudes have been described as, "a behavior pattern, anticipatory set or tendency, predisposition or specific adjustment to designated social situations, or, more simply, a conditioned response to social stimuli."[6] Studies about attitudes toward epilepsy including public attitudes or children's attitudes toward their epilepsy were published and indexed in PubMed as early as in the 1950s and 1940s, respectively.[7,8] However, negative attitudes toward epilepsy existed long before then. Attitudes can be conceptualized as both negative attitudes toward a person with epilepsy (could include attitudes of persons with epilepsy toward others with epilepsy) and negative attitudes of persons with epilepsy toward themselves.

Recently, the public health implications of stigma and the social exclusion that accompanies it have begun to be articulated.[9–11] It has been shown that stigma represents a potential risk factor for both physical[12] and mental health problems.[13] Stigma also generates large societal costs.[14] In the case of epilepsy, stigma and social exclusion have been shown to contribute to impairments in physical and mental health, reductions in educational and employment status, and limitations in social roles—in summary, to multiple aspects of quality of life.[15]

This article considers the experiences of stigma reported by people with epilepsy and their family members/informal caregivers. We address the dual issues of "felt" and "enacted" stigma and factors identified as predictive of such stigma. We also examine attitudes toward epilepsy, in both those with and without epilepsy of any age or race, and assess factors associated with attitudes. We were interested in attitudes in any population group (eg, general public, health care professionals, teachers, people living with epilepsy). This work was undertaken as part of a larger project by the International League Against Epilepsy (ILAE) Stigma Task Force examining stigma and attitudes in epilepsy, including tools for measurement and stigma-reduction interventions. This work was completed to inform gaps and future studies aimed at alleviating stigma and negative attitudes toward persons with epilepsy.

2 | METHODS

The ILAE Task Force on Stigma in Epilepsy conducted a systematic review of stigma and attitudes in epilepsy. The purpose of this article is to report on the findings from the review of studies that reported on stigma- and attitude-related factors, determinants, and reported frequency. The systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (unless otherwise specified).[16] The protocol was not originally registered with PROSPERO as the work preceded the launch of PROSPERO.

Key points

- Reported rates of both felt and enacted stigma vary both *across* countries and geographical regions and *within* them.
- Negative attitudes toward epilepsy represent a significant social comorbidity for persons living with epilepsy.
- Whatever the specific beliefs about epilepsy, the implications for felt and enacted stigma and negative attitudes show considerable commonality globally.
- A better understanding of the social meaning of epilepsy within specific cultural contexts and its practical implications is needed.
- An important finding highlighted in our review is the role of terminology about epilepsy in the production of stigma.
- Both quantitative and qualitative studies are needed to inform the development of relevant, meaningful, and targeted intervention studies.

2.1 | Search strategy

The search strategy (Appendix 1) was developed by study team members (many of whom are stigma experts) and a librarian experienced in the conduct of systematic reviews. The following databases were searched from 1985 to November 5, 2019: MEDLINE, Cochrane CENTRAL Register of Controlled Trials, PubMED, EMBASE, PsycINFO, Cochrane Database of Systematic Reviews, CINAHL, Health and PsychoSocial Instruments, Social Services Abstracts, Sociological Abstracts, SocINDEX, LILACS, and Web of Science. No restrictions were placed on the region or language of publication except that articles without an abstract that were not in English or French were excluded. Thus non–English-language articles were included if they had an English abstract and otherwise met our eligibility criteria. Search terms included but were not limited to epilepsy, attitudes, bias, discrimination, perceptions, social acceptance, and stigma (Appendix 1).

The reference lists of included articles were also manually searched to identify additional studies.

2.2 | Study selection

Abstracts were reviewed in duplicate by two independent reviewers (all study authors were involved) and were retained for full-text review if either reviewer noted that the abstract offered any evidence of original research on felt stigma and/or enacted stigma and attitudes toward epilepsy. Our population of interest was persons with epilepsy/family members/carers of all ages who had experienced stigma or negative attitudes. Our comparison group was persons without epilepsy if studies included a control group. Our outcomes were "stigma frequency/factors/determinants/predictors" and "attitudes frequency/factors/determinants/predictors." Papers related to such topics were independently reviewed to ensure that they reported on epilepsy-related stigma (felt or enacted stigma specifically addressed, rather than simply implied or where focus was on the attitudes or misconceptions that lead to stigma) and attitudes and/or perceptions. Disagreements were resolved by consensus and through the involvement of a third author as necessary.

2.3 | Data extraction

All study authors were involved in abstract review, full-text review, and data extraction, following training sessions. Two reviewers independently extracted data from included articles using a standard data collection form in two phases. In the first phase, an abbreviated data abstraction form was employed, recording study information that would be necessary to identify publications using the same data (ie, study location, data collection years, and sample size). When multiple articles reported data from the same study population, the most comprehensive article was used, although all information was extracted to ensure complete data were available for analysis. A full-length structured data-abstraction tool was then used in the second phase to capture additional variables including: region/country, study design, demographic characteristics of participants, tool targets (ie, persons with epilepsy, persons without epilepsy), and target characteristics (Appendix 2).

2.4 | Study quality

Appraisal of study quality for studies addressing stigma and attitudes was performed using a quality and validity questionnaire for observational cohort and cross-sectional studies from the National Institutes of Health (NIH).[17] The following were appraised: question/objective stated, study population specified/defined, participation rate ≥50%, subject recruited similarly, sample size/power description provided, exposure of interest measured prior to outcome, timeline sufficient for associations between exposure and outcome, examined different levels of exposure, exposure measures clearly defined/valid, exposure assessed more than once, outcome measures clearly defined/valid, outcome assessors blinded, loss to follow-up ≤20%, and confounding variables measured and adjusted.

2.5 | Data synthesis

Data from included full-text studies were tabulated and synthesized according to the ILAE-defined six main world regions: Asia-Oceania, Africa, Eastern Mediterranean, Europe, Latin America, and North America. Studies were characterized by whether they reported on: (1) felt or (2) enacted stigma, (3) negative attitudes toward a person with epilepsy, or (4) negative attitudes of a person with epilepsy toward oneself. Positive attitudes were also noted when mentioned. Descriptive statistics were calculated when appropriate. Otherwise, a qualitative synthesis of the literature was performed in view of the heterogeneity present between studies (ie, different scales used, different domain measures, different populations). No meta-analysis was performed. Therefore, heterogeneity and publication bias (along with other sources of bias) could not be evaluated.

3 | RESULTS

3.1 | Overview of studies on epilepsy-related stigma and attitudes

We reviewed 4234 abstracts, of which 893 were assessed for full-text eligibility (Figure 1). Overall agreement between the two reviewers at this stage was excellent, at 86.2%. A total of 358 studies met inclusion criteria in terms of addressing stigma and attitudes (frequency, tools, interventions), but only 132 addressed stigma and 210 addressed attitudes specifically (some studies looked at both topics), the topics of this particular systematic review. The most common reasons for exclusion (n = 601) at the full-text stage were that the studies were not original data (46.1%, 277/601), only reported on epilepsy-related knowledge (21.6%, 130/601), and only reported on quality of life in epilepsy (14.3%, 86/601). The ILAE region breakdown of studies was as follows: Asia-Oceania 24.3% (83/342), Africa 17.8% (61/342), Eastern Mediterranean 5.6% (19/342),

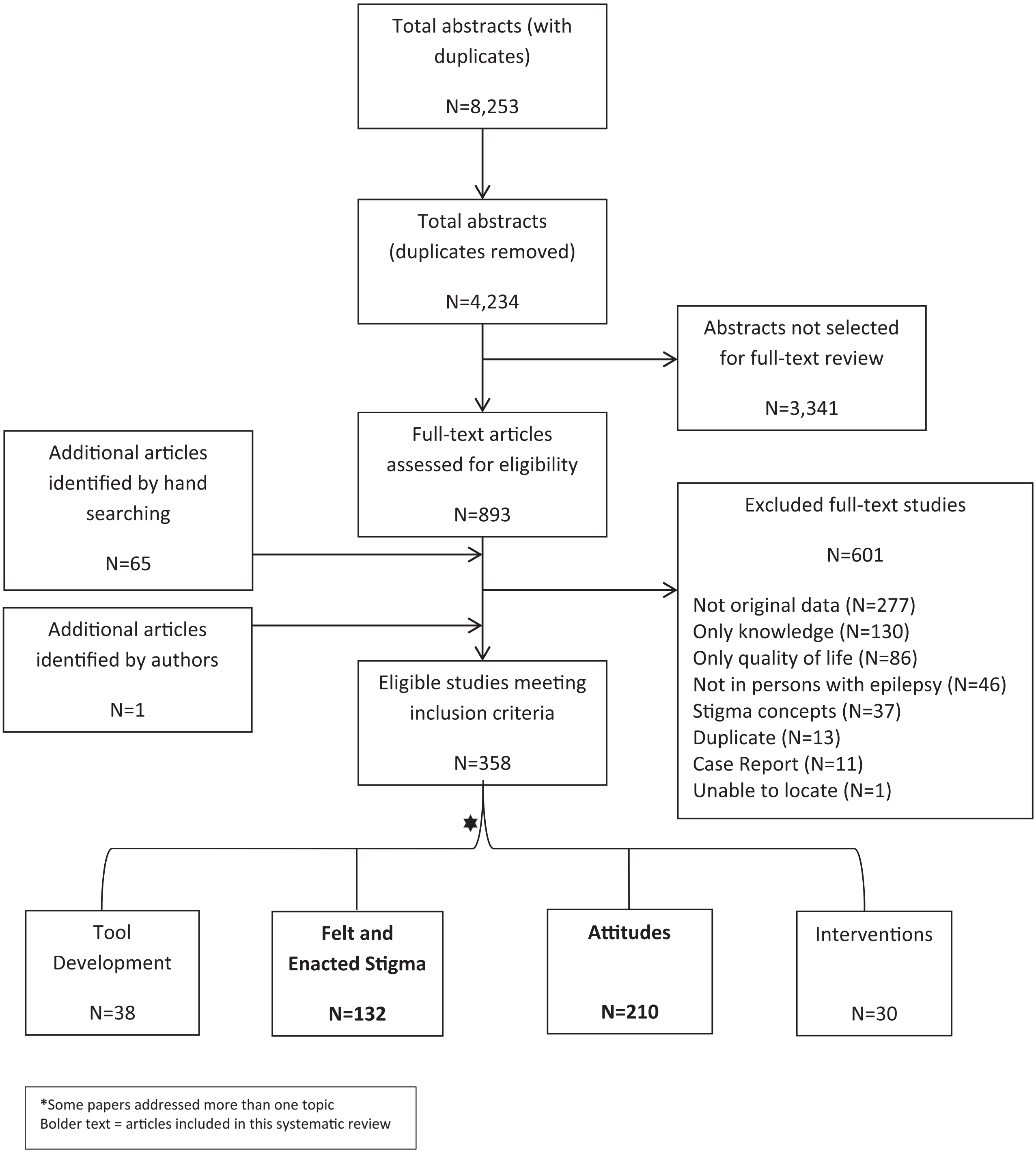

FIGURE 1 PRISMA Flow Diagram

Europe 25.7% (88/342), Latin America 8.5% (29/342), and North America 18.1% (62/342).

3.1.1 | Felt and enacted stigma

For each study the following information were collected: ILAE region of study, author, year of publication, country, study type, number of subjects, target respondents, age groups of respondents, how stigma was assessed, and main findings. The characteristics of the 132 studies that reported on epilepsy-related stigma are listed in Table S1.[4,18–148] Thirty-one studies were from Asia-Oceania, 20 from Africa, two from Eastern Mediterranean, 34 from Europe, 14 from Latin America, and 31 from North America. The dates of publication ranged from 1985 to 2019. The median number of included participants was 172 (range 9–5232). Ninety-five studies reported on felt stigma, 11 studies reported on enacted stigma, and 26 reported on both felt and enacted stigma.

3.1.2 | Attitudes toward epilepsy

Information was collected for each of the following studies: ILAE region of study, author, year of publication, country, study type, number of subjects, target respondents, age groups of respondents, how attitude was assessed, main and findings. Two hundred ten studies reported on epilepsy-related attitudes/perceptions, and the characteristics of these studies along with full references are reported in Table S2. Fifty-two studies (24.8%) were from Asia-Oceania, 41 (19.5%) from Africa, 9 (4.3%) from Eastern Mediterranean, 62 (29.5%) from Europe, 15 (7.1%) from Latin America, and 31 (14.8%) from North America. The dates of publication ranged from 1985 to 2019. The median number of included participants was 366 (range 13–19441). Two hundred ten studies reported on attitudes toward persons with epilepsy, of which 13 reported on self-attitudes in persons with epilepsy and 23 studies reported on both.

Table 1 is a summary of included studies stratified by type of attitude/stigma and ILAE region with the following information collated: sample size, study type, target respondents, age groups of respondents, ascertainment method, and validated scales used. Most studies that looked at enacted stigma and attitudes toward persons with epilepsy were not population-based and included mainly in adults. Data ascertainment methods were mainly via not validated questionnaires, and qualitative studies were at a minimum across all regions. Studies that looked at felt stigma and attitudes toward self were also mainly not population based and in adults. The majority used validated questionnaires. (Table 1) The following sections will describe overall results of (1) negative attitudes toward persons with epilepsy, (2) enacted stigma, (3) felt stigma, and (4) attitudes toward self. The descriptions of the foci of stigma and negative attitudes, predictors of such foci, results seen across different demographics, and their associations with other psychiatric diseases will be discussed.

1. Negative attitudes toward persons with epilepsy

The picture is a mixed one, ranging from generally positive/sympathetic[149–152] to largely negative attitudes.[153–157] There were some negative attitudes toward employment of people with epilepsy, although the results were not consistent across studies.[156,158–166] Overall, studies showed there was a reluctance to socialize or let children play with someone with epilepsy[158,167–170] and have a close relative marry someone with epilepsy.[159,170,171] Belief in the contagious nature of epilepsy, inappropriate local terminology, poor knowledge of the causes, and strong cultural and religious beliefs relating to epilepsy led to the preference not to marry persons with epilepsy or to employ them, and the rejection of friendship with persons with epilepsy.[66,68] In a few studies, responders were unwilling to socialize or befriend people with epilepsy,[161,172] would not have sexual relations with them,[161] and thought that people with epilepsy should not have children.[161,170] Reasons for the reluctance to befriend a person with epilepsy included worry about "catching" epilepsy, the burden of excessive responsibility, and not knowing what to do if a seizure happened.[173] Those who knew a person with epilepsy (ie, had personal proximity to the condition) or had some understanding of the clinical causes of epilepsy expressed more positive attitudes.[174] Attitudes toward marriageability of people with epilepsy were more hostile than those toward employment of people with epilepsy: A considerable majority of respondents held negative views that often entailed objection to marriage of their children to a person with epilepsy and to childbearing by women with epilepsy.[175–187] Of interest, although favorable knowledge and perception of epilepsy were reported among some students and resident populations, many still disapproved of their children being married to people with epilepsy.[164,184,185,188] Not only peer, but parental understanding of epilepsy, was also found to be poor and incorrect, often resulting in over-protectiveness, concealment for fear of stigma, and poor communication with children having epilepsy.[189] Compared to other chronic diseases such as AIDS, asthma, diabetes, and other neurological disorders, many expressed reluctance to befriend peers with epilepsy.[190–193]

Caregivers, friends, and relatives of people with epilepsy had a much more positive attitude toward epilepsy than did the general population.[194] Highschool students had higher rates of integrative attitudes compared to middle school students.[195] In some studies, teachers had a positive attitude,[196,197] supporting the training at regular schools and expecting excellent school results,[198] although personal knowledge of a student with epilepsy led to overprotection.[199] Nonuniversity students[165] and non-medical university students[166] were the least likely to say they would marry a person with epilepsy. In one study, university students were against marrying or even befriending people with epilepsy.[200] Even among population subgroups such as medical personnel and teachers, negative attitudes were commonly reported.[201–203] A study of family physicians stated that people with epilepsy should avoid demanding work and that they would not contribute to society; some even disagreed with people with epilepsy being free to marry and/or have children.[204]

Healthcare professionals found that fear was thought to be the main public attitude toward people with epilepsy.[117] Approximately 50% of neurologists in one study believed that many patients think that epilepsy "precludes living a normal life" and affected patients' willingness to seek and continue treatment.[205] Compared to school nurses, staff members were more fearful of children with epilepsy and responded inappropriately to seizures.[206] Studies of school teachers demonstrated a similar fear of seizures and children with epilepsy, coupled with poor knowledge and misconceptions about the disorder.[207–211]

Sex, age, and socioeconomic status were all associated with expressed attitudes.[175–187] Males,[155,167,168,212] older adults,[156,167,168,212–214] and persons of low socioeconomic background,[155,157] lower educational level,[156,157,167,212–214] and/or limited knowledge about epilepsy[155,167,212,214] were more likely to have negative attitudes. The following factors were associated with positive attitudes: knowing someone with epilepsy,[215,216] higher levels of education,[217–219] older age,[190] female sex,[190,219] urban living,[190] and higher income.[192] Better attitudes were noted in teachers with more teaching experience, higher education, female sex, and exposure to epilepsy students (ie, personal proximity to the condition).[220] A recurring reason for negative attitudes was the misconception that epilepsy is hereditary, untreatable, a form of psychiatric illness, or the result of supernatural forces.[180,184,185,207,208,210,221–227] Another study reinforced the hypothesis of strained parental relationships, which included attitudes such as rejection, anxiety, and doting toward children with epilepsy.[228]

2. Enacted stigma

Discrimination against people with epilepsy was seen consistently across five separate domains of daily living: school,[42,61,67,95,114] work,[42,46,61,67,68,114,116] social relationships,[42,61,67,68,95,114] marriage,[42,68,114] and family.[42,61,68,114] There was significant discrimination in schools and employment in the form of bullying, with increased disease burden and social exclusion; unemployment rates among the persons with epilepsy were higher than local unemployment rates, with examples of those who disclosed their epilepsy condition to a prospective employer reporting failing to get the job or being passed over for a promotion.[42,46,61,67,68,95,114,116] Younger people thought that enacted stigma would happen more often at work or school than at home or in personal relationships.[115] Social exclusion and rejection in childhood in individuals with epilepsy, and avoidance by friends, neighbors, and classmates were commonly reported.[48,102] Negative social relationships have been reported with peers including misunderstanding, bullying, being laughed at, and being threatened.[229] To circumvent anticipated shame, family members often concealed the diagnosis, withdrew the person with epilepsy from treatment, and socially isolated them.[43] A study in Togo highlighted how the practice of forehead scarification marked out persons with epilepsy for prejudice.[62]

In highschool students, significantly worse stigma scores were obtained when the term "epileptic" was used as a descriptor, as opposed to "people with epilepsy."[109] Students consistently thought that social relationships and prejudice on the part of others were the main sources of difficulties in epilepsy patients' daily lives.[115] A study of medical personnel, academic, and human service professionals reported that they felt that the most significant challenge to managing epilepsy was the lack of public understanding and accompanying enacted stigma, both more common in those with no personal experience of epilepsy.[146] Of interest, a study involving psychiatrists found that 48% considered themselves to be prejudiced against patients with epilepsy.[113]

Lack of knowledge and therapeutic difficulties were among the most commonly cited causes for epilepsy-related prejudice.[113] Factors associated with beliefs about enacted stigma among the general population were lower educational level, lower social class, epilepsy familiarity, and female gender.[107,108] Direct correlation between experience of and beliefs about enacted stigma and the severity and frequency of seizures were evident.[99,116]

3. Felt stigma

A common strategy for dealing with felt stigma was that of concealment, wherein patients avoided disclosing their epilepsy at work and those who lost their jobs attributed it to epilepsy.[52,66,116] Felt stigma seemed to be more dependent on pragmatic social factors than on sociocultural representations of epilepsy.[53] Approximately 60% of adult respondents in a study in Zambia agreed that they "feel some people are uncomfortable with me because of epilepsy; treat me like an inferior person and would prefer to avoid me." However, no relationship was found between felt stigma and age, sex, wealth, seizure type/frequency, or epilepsy stigmata in one study.[52] Perceptions of the individual were closely related to their feelings toward the condition. People with epilepsy often expressed deeply self-stigmatizing feelings, in particular being unable to mix with other people, to attend normal school, or to befriend others with fear of embarrassment of having a seizure.[84,94,100,105,114] Felt stigma in both children with epilepsy and family members were also associated with impaired academic performance.[55] In a study of all ages,

TABLE 1 Synthesis of Included studies stratified by type of attitudes/stigma and region

	Asia-Oceania ***N* = 46 studies**	**Africa** ***N* = 40**	**Eastern Mediterranean** ***N* = 16**
Attitudes toward person with epilepsy and enacted stigma			
Sample size	Mean = 643.65 Range 10–2610	Mean = 503.03 (excluding Grunitzky) Range = 66–3256	Mean = 1754.06 Range = 121–16500
Study type	Population based = 19 Non population based = 13 Unclear or Unspecified = 14	Population based = 16 Non population based = 12 Unclear or Unspecified = 12	Population based = 5 Non population based = 7 Unclear or Unspecified = 4
Target respondents	Persons with epilepsy = 5 General public = 23 Students = 4 Teachers = 6 Others = 8	Persons with epilepsy = 2 General public = 13 Students = 6 Teachers = 7 Others = 12	Persons with epilepsy = 0 General public = 8 Students = 2 Teachers = 2 Others = 4
Age group of respondents	Children = 3 Adults = 34 Both = 7 Not specified = 2	Children = 3 Adults = 25 Both = 10 Not specified = 2	Children = 2 Adults = 13 Both = 1
Ascertainment method	Quantitative = 43 • Validated = 15 • Not Validated/Unclear = 28 Qualitative = 3	Quantitative = 39 • Validated = 4 • Not Validated/Unclear = 35 Qualitative = 1	Quantitative = 14 • Validated = 6 • Not Validated/Unclear = 8 Qualitative = 2
Validated scales used	• Public Attitudes Toward Epilepsy Scale • Implicit Association Test • Stigma Scale for Epilepsy • Scale of Attitudes Toward Persons with Epilepsy (ATPE) • Knowledge, attitude and practice toward epilepsy • Malay Awareness, Knowledge, and Attitudes Epilepsy	• The semantic differential • The behavioral differential of Triandis	• Epilepsy Attitude Scale

	Asia-Oceania ***N* = 26**	**Africa** ***N* = 14**	**Eastern Mediterranean** ***N* = 2**
Attitudes toward self and felt stigma			
Sample size	Mean = 130 Range = 12–530	Mean = 152.79 Range = 4–423	Mean = 1946 Range = 45–3847
Study type	Population based = 0 Non population based = 24 Unclear or Unspecified = 2	Population based = 1 Non population base = 11 Unclear or unspecified = 2	Not population based = 1 Unclear or unspecified = 1
Target respondents	Persons with epilepsy = 18 Others = 8	Persons with epilepsy = 11 Other = 3	Persons with epilepsy = 2
Age group of respondents	Children = 4 Adults = 19 Both = 3	Children = 5 Adults = 9	Adults = 2
Ascertainment method	Quantitative = 20 • Validated = 17 • Not Validated/Unclear = 3 Qualitative = 6	Quantitative = 13 • Validated = 10 • Not Validated/Unclear = 3 Qualitative = 1	Quantitative = 2 • Validated = 1 • Not Validated/Unclear = 1 Qualitative = 0

Europe ***N* = 44**	**Latin America** ***N* = 14**	**North America** ***N* = 25**
Mean = 641.29 Range = 22–3875	Mean = 396.36 Range = 18–1850	Mean = 1291.72 Range = 27–19441
Population based = 12 Non population based = 17 Unclear or Unspecified = 15	Population based = 2 Non population based = 10 Unclear or Unspecified = 2	Population based = 1 Non population based = 9 Unclear or Unspecified = 15
Persons with epilepsy = 2 General public = 20 Students = 4 Teachers = 6 Others = 12	Persons with epilepsy = 1 General public = 1 Students = 6 Teachers = 3 Others = 3	Persons with epilepsy = 2 General public = 4 Students = 2 Teachers = 6 Others = 11
Children = 3 Adults = 32 Both = 7 Not Specified = 2	Children = 2 Adults = 10 Both = 2	Children = 4 Adults = 20 Both = 1
Quantitative = 42 • Validated = 5 • Not Validated/Unclear = 37 Qualitative = 2	Quantitative = 14 • Validated = 5 • Not Validated/Unclear = 9 Qualitative = 0	Quantitative = 24 • Validated = 8 • Not Validated/Unclear = 16 Qualitative = 1
• Stigmatization of patients with epilepsy questionnaire • Attitudes and Beliefs about Living with Epilepsy (ABLE) scale	• KAP Questionnaire (Knowledge, Attitude and Perception) • Stigma Scale of Epilepsy	• Stigma Scale of Epilepsy • Epilepsy Beliefs and Attitudes Scale • Attitudes Towards Persons with Epilepsy (ATPE) • Fishbein Expectancy-Value Model of Attitudes

Europe ***N* = 24**	**Latin America** ***N* = 10**	**North America** ***N* = 32**
Mean = 771.58 Range = 10–6156	Mean = 364.1 Range = 30–1850	Mean = 220.22 Range = 15–1023
Population based = 3 Not population based = 17 Unclear or unspecified = 4	Population based = 1 Non population based = 8 Unclear or unspecified = 1	Population based = 2 Not population based = 18 Unclear or unspecified = 12
Persons with epilepsy = 22 Other = 2	Persons with epilepsy = 7 General Public = 1 Students = 1 Other = 1	Persons with epilepsy = 27 Other = 5
Adults = 20 Both = 4	Children = 2 Adults = 5 Both = 3	Children = 6 Adults = 22 Both = 4
Quantitative = 23 • Validated = 17 • Not Validated/Unclear = 6 Qualitative = 1	Quantitative = 10 • Validated = 7 • Not Validated/Unclear = 3 Qualitative = 0	Quantitative = 32 • Validated = 23 • Not Validated/Unclear = 9 Qualitative = 0

TABLE 1 Continued

	Asia-Oceania ***N* = 26**	**Africa** ***N* = 14**	**Eastern Mediterranean** ***N* = 2**
Attitudes toward self and felt stigma			
Validated scales used	- Stigma Scale in Epilepsy - Epilepsy Stigma Scale - Child Stigma Scale - Parents Stigma Scale - Epilepsy Surgery Inventory-55 questionnaire	- Family Interview Schedule - Stigma Scale - Kilifi Stigma Scale - Epilepsy Stigma Scale	- Jacoby stigma scale

	Asia-Oceania ***N* = 11**	**Africa** ***N* = 7**	**East Mediterranean** ***N* = 1**
Attitudes toward both, and felt/enacted stigma			
Sample size	Mean = 579.36 Range = 59–2275	Mean = 157.86 Range = 16–338	533 participants
Study type	Population based = 2 Not population based = 4 Case-control study = 1 Unclear or unspecified = 4	Not population based = 4 Unclear or unspecified = 3	Not population based = 1
Target respondents	Persons with epilepsy = 8 Other = 3	Persons with epilepsy = 5 Other = 2	Persons with epilepsy and parents/caregivers = 1
Age group of respondents	Adults = 10 Children and Adults = 1	Adults = 5 Children and Adults = 2	Children and Adults = 1
Ascertainment method	Quantitative = 9 - Validated = 4 - Not Validated/Unclear = 5 Qualitative = 2	Quantitative = 6 - Validated = 2 - Not Validated/Unclear = 4 Qualitative = 1	Quantitative = 1 - Not Validated/Unclear = 1 Qualitative = 0
Validated scales used	- Knowledge Attitudes and Practice Questionnaire - Jacoby Stigma Scale	- Jacoby Stigma Scale	None

up to one in three patients with epilepsy said stigma was the worst part of having epilepsy.[129]

Felt stigma in epilepsy is associated with other psychiatric disorders. Higher scores for felt stigma were significantly associated with the presence of anxiety and, in some cases, depression.[53,60] Perceived stigma appeared to negatively impact subjective assessment of quality of life,[82] and those feeling highly stigmatized had higher rates of depression and anxiety.[91] Perceived stigma was also positively associated with maternal lack of confidence in managing their child's epilepsy, maternal depressive symptoms, and reduced family leisure activities.[111] Parental felt stigma was associated with increased depression and with increased perceived behavior problems in the affected child.[124]

The social experience of having epilepsy was often internalized by persons with epilepsy,[43] resulting in feelings of shame, self-pity, inferiority, and a sense of being a burden to others. Persons with epilepsy felt that people treated them differently; and they also accepted that they *were* different from others.[44] Persons with epilepsy could also feel that people were afraid of them.[39] In line with these results, patients who had been seizure-free for a year or more still felt embarrassed by having had them and that people did not understand their condition.[45]

Europe **$N = 24$**	**Latin America** **$N = 10$**	**North America** **$N = 32$**
• Stigma Scale for people with intellectual impairment • Stigma Scale of Epilepsy • Epilepsy Attitudes Scale • Epilepsy Stigma Scale • Jacoby Stigma Scale	• Stigma Scale of Epilepsy	• Child Attitude Toward Illness Scale (CATIS) • Child Stigma Scale • Epilepsy Stigma Scale • Jacoby Stigma Scale • Ryan (1980) scale • Link (1991) scale • Parent Stigma Scale • Liverpool Stigma Scale • Adult Stigma Scale • Perceived Stigma Scale • Mittan scale • Stigma Scale for Chronic Illness

Europe **$N = 20$**	**Latin America** **$N = 5$**	**North America** **$N = 5$**
Mean = 228.7 Range = 19–696	Mean = 243.8 Range = 100–498	Mean = 638.8 Range = 9–2931
Population based = 1 Not population based = 16 Unclear or unspecified = 3	Not population based = 5	Not population based = 2 Unclear or unspecified = 3
Persons with Epilepsy = 15 Other = 5	Persons with Epilepsy = 4 Other = 1	Persons with epilepsy = 3 Other = 2
Children = 2 Adults = 10 Both = 5 Not specified = 3	Children = 1 Adults = 3 Both = 1	Adults = 3 Children and Adults = 2
Quantitative = 18 • Validated = 6 • Not Validated/Unclear = 12 Qualitative = 2	Quantitative = 5 • Validated = 1 • Not Validated/Unclear = 4 Qualitative = 0	Quantitative = 3 • Validated = 0 • Not Validated/Unclear = 3 Qualitative = 2
• Self-esteem scale • Jacoby Stigma Scale • Child Stigma Scale	Stigma Scale of Epilepsy	None

Perceived stigma was shown to vary inversely with age, with younger groups tending to feel more stigmatized compared to the older population.[37,85] Higher levels of stigma were associated with lower self-esteem and poor quality of life.[24,36,40,47] Felt stigma was found to be higher in newly diagnosed patients than in patients with established epilepsy; and stigma scores declined with duration of illness, perhaps as a result of better seizure control due to treatment.[36] The presence of seizures emerged as the most common factor associated with higher degrees of perceived stigma,[77,88,90] with stigma increasing with seizure severity.[80] Patients who became seizure-free following surgery perceived less epilepsy-related stigma.[89] Alongside clinical factors, knowledge about epilepsy was an important predictor of degree of felt stigma.[93]

4. Attitude toward self

The impact of epilepsy on self-image and daily living was evident, with a heterogeneous pattern.[114] In a resource-limited setting, discrimination led to negative attitudes toward self, with additional suffering due to epilepsy entailed loss of self-esteem, vocational problems, emotional and financial burden, stigma, and an overall reduction in quality of life.[43] This trend was reflected in a study wherein persons with epilepsy were less likely to be educated, employed, and married as compared to healthy controls.[230] People with epilepsy described feeling a sense of burden even when the family and society in general did not hold a negative perception of epilepsy and under these conditions preferred to disclose their epilepsy condition rather than hiding it.[33] Women with epilepsy thought that they were more dangerous to others and thus were more likely to encourage others to avoid them and were less likely to receive help from their families.[48] In addition, as compared to clinical variables, social factors such as self-perception and coping strategies were thought to be better indicators of psychosocial adjustment among persons with epilepsy.[231] Self-esteem was positively correlated with knowledge about epilepsy and negatively with seizure frequency.[232] Attitudes toward epilepsy in those affected were related to beliefs about whether it was contagious.[52]

Many people with epilepsy tended to see themselves as less valuable, adaptable, dependable, mature, stable, successful, well-adjusted, and happy than persons without epilepsy.[233] People with epilepsy described themselves as unpredictable and often unable to cope with their life. Ongoing seizures were associated with an increase in the perception that epilepsy had a significant impact on daily life.[86,88] Although children expressed feelings of embarrassment and fear of discovery, they had an optimistic view, feeling that epilepsy would not significantly affect their lives, ambitions, or future choices.[234] Fear of mockery was identified as the reason for not performing social activities[117] and sport, particularly in adolescents.[235]

Almost half of adults with epilepsy believed that the general public had negative feelings toward them, influencing their self-perception.[236] Worse attitudes toward illness were associated with being an adolescent girl,[237] older age of adolescence,[237] more severe epilepsy,[130,237] poorer self-concept,[130,238] and poorer academic achievement.[239] Children with epilepsy had poorer attitudes regarding their condition than did children with asthma.[238] One in three patients expressed that there is shame and disgrace associated with having epilepsy.[240]

3.2 | Study quality

Fifty-nine percent (124/210) of studies that addressed attitudes were of poor quality and 41% (86/210) were of fair quality; 48% (63/132) of studies that addressed stigma were of poor quality and 52% (69/132) were of fair quality. (Tables S3 and S4).

4 | DISCUSSION

Our analysis highlights a number of key issues around the prevalence of and factors associated with stigma in epilepsy, the understanding of which is central to attempts at stigma reduction. The first point to note is that there is no clear divide between the different geographical regions for reported prevalence of either felt or enacted stigma: rather, reported rates of both vary *across* and *within* them, often quite markedly. Among the included studies, across-region rates of felt stigma were as low as 10% (in Pakistan) to as high as 66% (in Mexico). Within world regions, one study in Europe found that across the entire European region, more than half of persons with epilepsy felt stigmatized[94]; but that there were large differences in levels of felt stigma, with rates lowest in Spain (32%) and highest in France (66%). Rates of enacted stigma similarly vary widely. For example, a staggering 86% of people with epilepsy in one Brazilian study reported active discrimination on the part of employers, with 40% reporting having been fired because of their condition.[114] In one Korean study, more than half of people with epilepsy who revealed their condition to a prospective employer reported that they had failed to get the job.[46] In one UK study, almost one third of people with epilepsy considered that having epilepsy had made it more difficult for them to secure employment.[101] We also found that negative attitudes toward persons living with epilepsy have been reported globally, and that those contributing to these poor outcomes are from all paths of life and include but are not limited to teachers, students, health care professionals, the general public, and even those living with epilepsy themselves. Unfortunately, true estimates of acts of discrimination, although often reported by persons living with epilepsy in our clinical practices on a daily basis, are seriously lacking.

Key to understanding this variation is an appreciation of the social meaning of epilepsy within specific cultural contexts and its practical implications for fulfillment of social roles. It has been hypothesized that the different features of stigmatizing illnesses (attribution of responsibility, degree of visibility and disruptiveness, perceived danger to others) will carry different weights in different cultural settings[241]; and that epilepsy can be characterized as stigmatizing to greater or lesser degrees along each of these axes. Several of the studies reviewed here support this position, highlighting that these theoretical constructs are central at both macro- (eg, societal) and micro- (eg, family) environmental levels, informing the attitudes and behaviors of relevant "others" and hence the lived experience of stigma of people with epilepsy. Examples are those from China,[242] where epilepsy is commonly believed to be the result of bad fate, heredity, and supernatural forces and is, therefore, imbued with a sense of moral blame; and in countries in sub-Saharan Africa, where epilepsy is commonly thought to be contagious[241,243,244] and to have supernatural origins.[97,244] These results highlight the need to educate local communities wherever they are in the world, and inculcate perceptions and attitudes that promote rather than inhibit early disclosure of epilepsy and early care-seeking behavior.[64]

Whatever the specific beliefs about the causes and meaning of epilepsy in specific parts of the world, the implications show some considerable similarity. Studies worldwide commonly report a high degree of felt stigma among people with epilepsy and often also their families. They also demonstrate clear relationships between felt stigma and impaired quality-of-life overall and within specific domains, for example psychological well-being—although the direction of effects is unclear and not easily disentangled. In relation to enacted stigma, securing and remaining in employment emerges as an almost universal issue, as does education. Social exclusion—for example, in relation to marriageability—is also commonly reported worldwide.[9,47,66] However, a major difficulty in examining the issue of enacted stigma is that many studies focus on subjective assessments of its (likely) prevalence, rather than seeking out objective evidence that it has actually occurred. And, although studies that report public attitudes (addressed elsewhere) may act as surrogate markers of the likelihood of enacted stigma, the distinction between negative attitudes and their translation into acts of discrimination requires further examination.

Our systematic review found that misconceptions and negative attitudes are present regardless of the type of respondent (eg, general population, teachers, students, health care professional) or type of country (eg, low/middle vs high resource).[7,156,158,177,178,245] North American studies found that people were less comfortable spending time outside of work with people with epilepsy[192] and that epilepsy had a negative effect on the classroom equal to that of AIDS.[190] Studies frequently reported objection to one's child marrying someone with epilepsy in the general population.[177,246] Although, teachers and healthcare professionals in some studies were in agreement with the concept of persons with epilepsy marrying, a significant number did not accept their own children marrying someone with epilepsy.[200,206]

Our analysis identified a number of factors associated with felt and enacted stigma. For enacted stigma, these included lack of familiarity and, linked to this, a low level of knowledge about epilepsy; also lower educational and socioeconomic level, rural compared to urban dwelling, and religious grouping. Earlier age at onset, more recent and more frequent seizures that are persistent, younger age, poorer education, and socioeconomic status were generally associated with a higher likelihood of felt stigma. Other predictive factors suggested in only single or a few studies—for example, the role of religious group identity—could usefully be explored further in future work. It is important to bear in mind that stigma perception may vary depending on who is the focus of study.[247]

With time, we have seen encouraging improvements in attitudes and practice toward persons with epilepsy. Significant increases in integrative attitudes in the overall population correlating with decreases in stigmatizing attitudes were seen in a Brazilian study.[248] In a 30-year North American study interviewing the CEOs of the largest employers in the area, it was seen that many CEOs would dismiss an employee because of a seizure in the earlier time period, whereas none would in the most recent study.[249]

An important finding highlighted by one study in our review is the role of language in the production of stigma. In a study conducted in Brazil,[108] stigma scores were higher where the term "epileptic" was used as a descriptor than when the phrase "people with epilepsy" was offered. Others have also noted the potential impact of terminology. For example, in one US study, employers were presented with letters of application for a job from fictional applicants, in which their condition was variously described as "epilepsy," "seizure disorder," and "seizure condition," and found that "epilepsy" was more positively perceived than the other two labels.[250] This issue of labeling is one that campaigning groups continue to address. Concerns regarding how best to refer to persons with certain health conditions are not exclusive.[251] Recommendations have been put in place that the word "epileptic" be discarded and "person with epilepsy" be used.[252] A Brazilian Global Campaign Against Epilepsy study showed that the word "epileptic" should not be used because it disseminated greater stigma and negative attitudes toward those with epilepsy.[109] Referring to those living with epilepsy as "person with epilepsy" rather than "epileptic" is thought to be less negative, whereas supporting personhood before disability and thus may not negatively confine expectations of those being referred to. However, a recent study in the UK replicated the Brazilian study but did not find significant differences, suggesting variations between populations.[253]

It has been suggested that although the theoretical distinction between felt and enacted stigma is well supported by research, the question needs to be addressed as to whether differing clinical realities (including, eg, the size of the treatment gap) across and within different world regions means the weight of importance of felt vs enacted stigma will also differ widely.[254] Future stigma reduction interventions would need to consider the relative importance of each element within specific sociocultural contexts.[65] It has been shown that this may be variable even between particular population sub-groups in the same geographical location. For example, in work in Zambia, researchers found that police officer attitudes were largely determined by contagion beliefs, whereas key for teachers was proximity to someone with epilepsy, and for clerics whether or not they recognized epilepsy as a biomedical condition. This suggests that determining factors for felt and enacted stigma are highly specific not just to macrocultural factors, but also to microcultural ones such as social group and role—with significant implications for targeting stigma reduction.

For this review, we considered studies dating back to 1985. However, scientific and technological advances worldwide in the years since have meant that the situation for people with epilepsy may have changed significantly in relation to health and social care in some of the included countries, and as a result also in relation to the positioning of epilepsy as stigma—hopefully for the better. Within the limits of the review, studies conducted within a single region over a period of time (for example, the US series by Caveness and Gallup[255]) indicated that public attitudes can be improved and as a result the degree of stigma can decrease over time. However, replication of such studies within the same country or cultural setting is uncommon, meaning that such time-related comparisons are rare and not meaningful in the context of studies included in this review. Despite the all-encompassing search strategy and extensive literature search we completed (13 databases, any language), it is possible that some articles were missed. Almost every study was cross-sectional in nature. Prospective studies were scarce and, if present, of very short duration. There was often a lack of details about source of ascertainment and sampling methods, years of data collection, and methods of questionnaire administration. Many studies ascertained attitudes without using a validated questionnaire or without culturally specific modules.

In summary, our review shows that quantitative studies of prevalence and predictive factors for stigma provide important baseline data. However, qualitative studies are also important for understanding the variable prevalence of different forms of stigma, and to elucidate its whys and wherefores. Both types of study are needed to inform the development of relevant, meaningful, and targeted intervention studies. Furthermore, efforts to reduce stigma and improve the negative attitudes that promote and sustain it must be capable of addressing multiple and variable factors. The design of community-based interventions to target this real-world concept is complex when compared to the classic randomized clinical trial (the "gold standard" for health care research), but there are examples both in the field of epilepsy[236] and other stigmatizing conditions that can inform future efforts in the context of epilepsy.[256,257] Although funding for such studies is in short supply, the need for investment is compelling. Overall, although we identified a high number of studies addressing the topic of attitudes in epilepsy, our knowledge about the true incidence of discriminatory behaviors as well as the mechanisms of discrimination and negative attitudes is still limited. Box 1 provides additional recommendations for future research. Although improving knowledge on epilepsy was usually correlated with a decrease in negative attitudes, familiarity or close contact with persons with epilepsy was shown to have different effects in different regions, emphasizing the need for culturally tailored interventions. Future studies evaluating the short- and long-term outcomes associated with poor attitudes and discrimination such as quality of life, employment, relationships, and costs to those living with epilepsy and to society are urgently needed. Although progress has been made in the fight against stigma and discrimination against those living with epilepsy, future robust trials to combat negative attitudes and discrimination are needed. Patient-centered multifaceted longitudinal intervention studies that incorporate education, advocacy, increased contact between those living with and without epilepsy, legislation, and reduction in the treatment gap will likely be most successful.

BOX 1 Recommendations for future research

Investigators who want to measure attitudes or stigma in future studies are encouraged to:
- use established measurement instruments to enable cross-comparisons
- investigate the true incidence of discriminatory behaviors, as well as the mechanisms of discrimination and negative attitudes
- emphasize the need for culturally tailored interventions
- evaluate the short- and long-term outcomes associated with poor attitudes and discrimination such as quality of life, employment, relationships, and costs to those living with epilepsy and to society

Future robust trials to combat negative attitudes and discrimination are needed.

Patient-centered multifaceted longitudinal intervention studies that incorporate education, advocacy, increased contact between those living with and without epilepsy, legislation, and reduction in the treatment gap will likely be most successful.

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CONFLICT OF INTEREST

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DISCLAIMER

This report was written by experts selected by the International League Against Epilepsy (ILAE) and was approved for publication by the ILAE. Opinions expressed by the authors, however, do not necessarily represent the policy or position of the ILAE.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher’s website.

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APPENDIX 1

EPILEPSY AND STIGMA

Search Strategy

November 2019

MEDLINE (OVID)

Cochrane CENTRAL Register of Controlled Trials (OVID)

1. exp *Epilepsy/
2. (epilepsy or epileptic*).tw.
3. 1 or 2
4. exp Prejudice/ or exp Social Stigma/ or exp Stereotyping/
5. attitude/ or attitude to health/
6. Public Opinion/
7. Social Desirability/ or Social Perception/
8. (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotype* or stigma).tw.
9. 4 or 5 or 6 or 7 or 8
10. 3 and 9
11. limit 10 to animals
12. limit 10 to (animals and humans)
13. 11 not 12
14. 10 not 13
15. limit 14 to (english or french)
16. limit 14 to abstracts
17. 15 or 16
18. limit 17 to yr="1985 -Current"

PubMED

1. Epilepsy[MAJR]
2. (epilepsy or epileptic*)[tiab]
3. 1 or 2
4. Prejudice[MeSH] or Social Stigma[MeSH] or Stereotyping[MeSH]
5. attitude[MeSH:noexp] or attitude to health[MeSH:noexp]
6. Public Opinion[MeSH:noexp]
7. Social Desirability[MeSH:noexp] or Social Perception[MeSH:noexp]
8. (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotype* or stigma)[tiab]
9. 4 or 5 or 6 or 7 or 8
10. 3 and 9
11. limit 10 to (english or french)
12. limit 10 to abstracts
13. 11 or 12
14. limit 13 to yr="2010-Current"

EMBASE (OVID)

1. exp *epilepsy/
2. "*seizure, epilepsy and convulsion"/ or *seizure/
3. (epilepsy or epileptic*).tw.
4. 1 or 2 or 3
5. stigma/
6. social psychology/
7. attitude/ or attitude to health/ or attitude to illness/ or attitude to mental illness/ or health personnel attitude/ or patient attitude/ or social worker attitude/
8. health personnel attitude/ or nurse attitude/ or physician attitude/
9. public opinion/
10. social desirability/
11. perception/
12. social discrimination/ or employment discrimination/
13. social aspect/
14. social attitude/
15. (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotyp* or stigma*).tw.
16. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. 4 and 16
18. limit 17 to english language
19. limit 17 to abstracts
20. 18 or 19
21. limit 20 to animals
22. 20 not 21
23. limit 22 to (conference abstract or conference paper or "conference review")
24. 22 not 23
25. limit 24 to yr="1985 -Current"

PsycINFO (OVID)

1. exp *epilepsy/
2. (epilepsy or epileptic*).tw.
3. 1 or 2
4. stigma/ or labeling/ or social acceptance/ or social approval/
5. social discrimination/ or disability discrimination/ or employment discrimination/
6. attitudes/ or community attitudes/ or counselor attitudes/ or health attitudes/ or public opinion/ or stereotyped attitudes/
7. disability discrimination/
8. "disabled (attitudes toward)"/ or "mental illness (attitudes toward)"/ or "physical disabilities (attitudes toward)"/
9. exp health personnel attitudes/
10. prejudice/ or disability discrimination/ or employment discrimination/

11. exp social perception/ or stranger reactions/
12. (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotyp* or stigma*).tw.
13. 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. 3 and 13
15. limit 14 to animal
16. limit 14 to (animal and human)
17. 15 not 16
18. 14 not 17
19. limit 18 to yr="1985 -Current"
20. limit 19 to english language
21. limit 19 to abstracts
22. 20 or 21

Health and PsychoSocial Instruments Database (OVID)

Cochrane Database of Systematic Reviews (OVID)

1. (epilepsy or epileptic*).tw.
2. (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotype* or stigma).tw.
3. 1 and 2
4. limit 3 to (english or french)
5. limit 4 to yr="1985 -Current"

CINAHL (EBSCO)

1. MH "Epilepsy")
2. TI (epilepsy or epileptic*) OR AB (epilepsy or epileptic*)
3. 1 or 2
4. (MH "Stigma") OR (MH "Attitude") OR (MH "Attitude to Health+") OR (MH "Attitude to Illness+") OR (MH "Consumer Attitudes") OR (MH "Cultural Bias") OR (MH "Cultural Sensitivity") OR (MH "Family Attitudes+") OR (MH "Patient Attitudes") OR (MH "Social Attitudes") OR (MH "Discrimination") OR (MH "Perception") OR (MH "Self Concept") OR (MH "Prejudice") OR (MH "Stereotyping")
5. TI (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotype* or stigma) OR AB (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotype* or stigma)
6. 4 or 5
7. Limit 6 to 1985-present

Social Services Abstracts (CSA)

Sociological Abstracts (CSA)

1. (epilepsy or epileptic*)[All Fields]
2. (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotype* or stigma)[All Fields]
3. 1 and 2

SocINDEX (EBSCO)

1. (epilepsy or epileptic*)[All Fields]
2. (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotype* or stigma)[All Fields]
3. 1 and 2
4. limit 3 to (english or french)
5. limit 4 to yr="1985 -Current"

LILACS (Latin American and Caribbean Literature)

1. Epilepsy[Subject Descriptors/Words]
2. Prejudice or Social Stigma or Stigma or Stereotyping or Attitude or Public Opinion or Social Desirability or Social Perception or Perception Social Acceptance or Social Approval[Subject Descriptors/Words]
3. 1 and 2

Web of Science (ISI)

1. (epilepsy or epileptic*)[Topic]
2. (attitudes or discriminat* or perceptions or prejudic* or social accept* or social approval or social desirability or stereotype* or stigma)[Topic]
3. 1 and 2
4. limit 3 to (english or french)
5. limit 3 to 1985–2011

APPENDIX 2

FREQUENCY AND FACTORS ASSOCIATED WITH STIGMA

Reference Number

Author Last Name

Reviewer

Publication Year

WHO Region

(select all that apply)

Asia, Pacific
Asia, Central
Asia, East
Asia, South
Asia, Southeast Australasia
Caribbean
Europe, Central Europe, Eastern Europe, Western

Latin America, Andean Latin America, Central Latin America, Southern Latin America, Tropical North America

North Africa/Middle East Oceania

Africa, Central

Africa, East

Africa, Southern Africa, West

Country(ies)

Province/ City, etc

Urban

Urban

Rural

Both

Not specified

Start Year Data

End Year Data

Study Type

Population Based

Not Population Based

Unclear or Unspecified

Number of Participants

Response Rate (%)

Target Respondents (select all that apply)

Patients with epilepsy

Parent or caregiver of person with epilepsy Medical personnel (eg, nurses, physicians, etc) Students

General Public

Other (specify)

Age Groups of Respondents (select all that apply)

Children (all ages)

Adolescents only

Adults only

Older adults only

All age groups

Not specified

Mean/Median Age of Respondents (if provided)

Age Range of Respondents

Number of Female Participants

Percentage of Female Participants

Number of Male Participants

Percentage of Male Participants

Area Addressed (select all that apply)

Stigma (felt)

Stigma (enacted)

Attitudes (toward self)

Attitudes (toward person with epilepsy)

Comments

How was stigma and/or attitudes assessed? (select all that apply)

Stigma scale/questionnaire (validated)

Stigma scale/questionnaire (not validated or unclear)

Attitude scale/questionnaire (validated)

Attitude scale/questionnaire (not validated or unclear)

Other (specify)

Results of stigma measurement (descriptive)

Were any factors associated with stigma (select all that apply)

Sex

Age

Educational level (define categories) Income

Other (specify)

Statistics used to look at factors associated with stigma and results

If attitudes assessed, what did they look at? (select all that apply)

Social contacts (eg, playing with other children, etc)

Marriage

Employment

Driving

Other (specify)

Results of attitudes measurement (descriptive)

Were any factors associated with attitudes (select all that apply)

Sex

Age

Educational level (define categories) Income

Other (specify)

Statistics used to look at factors associated with attitudes and results

Other findings (miscellaneous)