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Epilepsy misconceptions and stigma reduction: Current status in Western Countries

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Abstract

Objective: This systematized literature review identified reports describing epilepsy misconceptions in the developed Western countries and research interventions focused on reducing these misconceptions.

Materials and Methods: English language publications from January 2004 to January 2015 that described original research conducted in Europe, North/Central/South America or Australia on misconceptions about epilepsy among the general public.

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Results: 81 publications were selected. Most studies were conducted in the Americas (N=30) and Europe (N=31). Misconceptions and attitudes about epilepsy were assessed among clinical providers (N= 9), family members of people with epilepsy (PWE, N=5), teachers (N= 11), students (N=22), and the general public (N= 25). Most studies used structured questionnaires, sometimes adding open-ended questions. Misconceptions reflected socially exclusionary attitudes directed at PWE, ignorance about treatment, and over-generalizations that are stigmatizing when applied to all PWE. Misconceptions were more prevalent in those with less education, lower socioeconomic status, and no exposure to PWE. There were only 12 intervention studies. While intervention studies were generally effective in improving attitudes, many were targeted to healthcare and education settings, were time intensive, and impractical for broad general population implementation. None incorporated newer technology-based strategies regarding effective health communication approaches.

Conclusions: Types of epilepsy misconceptions were similar in reports published over the last decade, although most referred to misconceptions that have already been previously described. Existing questionnaires may fail to identify more subtle forms of current misconceptions and negative attitudes. Few interventional studies specifically target epilepsy stigma. Practical and broad scalable approaches to de-stigmatize epilepsy may help reduce misconceptions.

Keywords

epilepsy; seizures; stigma; misconceptions; health communication

Introduction

Throughout history, epilepsy has been a misunderstood and highly stigmatized disorder. The word itself comes from ancient Greek and refers to “being seized by forces from without,” a reference to the supposed supernatural origins of the disease.[1] Divine retribution, demonic possession, and contagion have been common explanations for seizures, and until the late 1800s, people with epilepsy (PWE) were often incarcerated as “criminally insane.”

Over time, negative attitudes toward PWE have diminished,[2] yet a significant proportion of the population remains uninformed and stigma is still a major source of stress and limitations for PWE. The Global Campaign Against Epilepsy (GCAE): Out of the Shadows, a joint venture from the World Health Organization, the International League Against Epilepsy, and the International Bureau of Epilepsy, was established in 1997 with the mission of improving acceptability, treatment, services, and prevention of epilepsy worldwide.[3] Perhaps appropriately, the primary focus of the GCAE has been in the developing world, where the stigma and dearth of knowledge concerning epilepsy have been the most severe. There is a large literature on the subject and some improvements for PWE living in these regions of the world.

By comparison, in Western developed countries, the degree of misconceptions and stigmatizing attitudes is unclear, even with national laws such as the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA). Relatively less effort has focused on the myths and misconceptions surrounding epilepsy in modern

Western society, the impact on PWE, and means to overcome these misconceptions and stigma.

The Institute of Medicine (IOM) highlighted epilepsy stigma as an important priority, stressing the continuing negative effects of stigma on PWE.[4] Stigmatized PWE have lower self-esteem, greater social isolation, poorer psychological health, lower quality of life, and worse epilepsy control.[5–10] The IOM noted some specific public health initiatives to reduce stigma associated with epilepsy and other conditions, but there is still substantial room for improvement and adaptation of other successful approaches, such as stigma reduction initiatives for mental health disorders need to be considered [11–13] Initiatives to reduce mental health stigma can potentially inform new strategies to change attitudes and facilitate a supportive, positive, and socially inclusive environment for PWE.

We sought to understand the recent literature on misconceptions and stigma surrounding epilepsy in Western societies and to identify key information relevant to understanding and modifying these misconceptions in order to limit stigma in our own society. To this end, we conducted a literature review focused on epilepsy stigma over the last decade and identified key epilepsy stigma themes in these studies. We were especially interested in research that evaluated epilepsy stigma reduction interventions and summarized the specific formats and health communication approaches in which the stigma-reduction interventions were delivered.

Materials and Methods

Our investigations involved three levels of literature review all focused on manuscripts published from 2004 to January 2015 to ensure contemporary relevance: 1) A survey of the original reports on epilepsy stigma with emphasis on country or region of the world of origin; 2) A systematic review of those original reports that addressed misconceptions and attitudes of the general public (people without epilepsy) toward PWE in Western countries; and 3) A focused assessment of articles presenting interventions specifically designed to reduce epilepsy stigma in Western settings.

1.1. Literature Review Search Strategy

PubMed, Web of Science and PsycINFO databases were searched for original research studies and reviews published in English between 2004 and January 2015. Search terms used were seizure*, epilepsy, myth*, misconception*, stigma, bias, restriction*, discrimination*, with keyword 1: epilepsy or seizure*, and keyword 2: myth* or misconception* or stigma or bias or restriction*or discrimination*; (*) was used as wildcard, to include several forms of the terms. A second search was done using Web of Science, with the same keywords, and intervention* or program* or education* as second keywords.

Another, less detailed search was done using Web of Science using keywords along with discrimination*, restriction*, myth* or stigma, as secondary keywords. Results from this search were used to identify articles based on the country or region of origin (where research was conducted) and the type of report (original, meta-analysis, review), in order to determine the geographical distribution of research projects on epilepsy myths and stigma.

As much of this literature was combined with literature on health-related quality of life (HRQOL), HRQOL literature was included if it appeared to address stigma. Articles that addressed very specific situations (e.g. stress surrounding epilepsy surgery) were excluded.

1.1.1. Literature reflecting the Western world—Inclusion criteria were 1) Studies of misconceptions about epilepsy among people who did not have epilepsy in the general population or in subgroups defined by role or occupation (e.g. teachers, college students); 2) Original research (randomized controlled trials, prospective non-randomized controlled and uncontrolled studies); and 3) Published in English. Reviews on epilepsy stigma from Europe, the Americas, and Australia were also used to identify additional studies potentially missed in the initial search. We excluded studies focused on self-perceived stigma in PWE. Studies that reported on both PWE and those without epilepsy were only included if the non-epilepsy group misconceptions were reported separately. The search results used to illustrate the distribution of research projects on epilepsy myths and misconceptions included all countries and research on both felt and enacted stigma. This systematic review focused on stigma attitudes as reported in the general population and not stigma experienced or reported by PWE.

1.1.2. Interventional Studies—In order to help inform the planning of future intervention studies, each interventional study was assessed for the specific health communication strategies used to deliver anti-stigma messages. Because this team of investigators is developing a stigma reduction approach targeted to young adults in the general public, we flagged as a particular area of focus, those interventions targeted to a young adult audience.

1.2. Selection of publications

All abstracts were pre-screened by one reviewer for relevance, based on title and abstract information. Abstracts were then assessed by a five-member review team for inclusion. Initially, all reviewers evaluated a list of the same 20 abstracts to ensure consistent application of inclusion/exclusion criteria. Discrepancies were discussed until consensus was reached and inclusion/exclusion criteria were refined as necessary. Once the inclusion/exclusion criteria were finalized, all abstracts were reviewed by two independent reviewers to determine suitability for further in-depth review.

1.2.1. Data collection, synthesis and reporting.—Reviewers used a structured data extraction form modeled on other systematic reviews and recommendations.[14–17] Reports were also assessed to see whether they included 1) An active intervention to reduce epilepsy misconceptions or stigma, 2) A health communication approach, and 3) A focus on young adults aged 18–29 years.

Results

1.1. Literature Review

To understand the cultural and geographic emphasis on stigma in epilepsy research, we performed a Web of Science search for articles published between 2004 and 2015 referenced under the key word epilepsy or Seizure* combined with any of the words stigma, myth*, discrimination* or restriction*. After excluding duplicate references, references that were review papers, meta-analyses, editorials, or commentaries only without original data, and references that were very targeted to a very specific situation (e.g. epilepsy surgery), we identified 237 original research reports that examined stigma and related constructs. These included studies of attitudes of individuals in the general population as well as studies about felt stigma among PWE or their caregivers. We extracted information about the country or countries in which the research was performed based on the title when possible or review of the abstract. When necessary, we reviewed the methods section from the actual report. The countries were grouped by region of the world to demonstrate the relative amounts of research being performed in these different areas (Figure 2). Some studies did not fall into a single region (N=6) or where done based on on-line resources such as YouTube (N=4). They are not plotted but were included in the denominator.

1.2. Overall description of Western studies

Eighty-one publications met inclusion criteria (Figure 1). Publication frequency is fairly uniform, except for a peak in 2007, which reflects several articles published by one group in Brazil (Figure 2). Most studies were from North America (N=27), Europe /Turkey, (N=32), and Central/South America (N=19). Two were from the Caribbean and one from Australia. The studies included assessment of misconceptions among clinical providers (N= 9), family members (N= 5), teachers (N= 11), students (elementary, secondary or professional schools, and universities) (N= 22), and the general public (N= 25). Eight studies analyzed social media content/sources including YouTube and Twitter. Studies were highly variable in format, design and quality.

Many studies combined assessment of knowledge and attitudes about epilepsy. Factual information about PWE was not always readily separated from some misconceptions; for example, while it is true that epilepsy does impose activity limitations (such as driving a car) for some PWE, it is not true that everyone with epilepsy is completely disabled.

1.3. Assessment of epilepsy misconceptions

Many studies used a structured, closed-ended questionnaire, either published previously by others or created by the authors, to assess epilepsy misconceptions, stigma or attitudes. A number of questionnaires were based on the surveys used by Caveness and Gallup.[18,19–28] Bishop et al, developed a questionnaire based on the assessment of Antonak and colleagues.[29–32] Fernandes et al, [33] developed the Stigma Scale of Epilepsy (SSE), which was used in a number of studies, often with some modifications. [34–40] Martiniuk et al, developed the “Thinking about epilepsy” questionnaire, which they used in a number of studies, [41–43] and Zanni et al, used the Brazilian version of The Epilepsy Beliefs and Attitudes Scale (EBAS).[44]

Only a handful of studies used open-ended, qualitative, or non-standardized formats for data collection. These provided some novel insights. A study from Mexico,[45] which utilized in-depth interviews with patients, care-givers, and medical providers, indicated that if seizures were fully controlled, there was no epilepsy stigma, implying that patients might be to blame if their seizures were not adequately controlled.

1.4. Characterization of epilepsy misconceptions

1.4.1. Epilepsy misconception themes—Closed-ended instruments used to assess misconceptions tended to reflect beliefs or attitudes that have been previously well-established. Misconceptions (Table 1) fell into several categories: (A) Social status/integration; (B) Employment; (C) Associated conditions; (D) Restrictions and limitations; (E) Cause/Nature; (F) Treatment and prognosis; and (G) First Aid. There was a relatively high degree of similarity across studies that identified misconceptions, but given the diverse target populations and methodologies across studies, we could not compare how often these misconceptions occurred across various sub-groups.

1.4.2. Public perception of how epilepsy affects PWE—Several studies noted that survey respondents who do not have epilepsy expressed positive attitudes towards PWE, but also felt that PWE experience discrimination from society and difficulties in relationships and work. Respondents noted they would conceal a diagnosis of epilepsy because of those concerns.[19; 22; 40; 46] In a study[24] of healthy people visiting medical centers in Greece, when asked *"If a person close to you was to have a disease which one would you "prefer" it to be?"* and given a choice of five chronic conditions, respondents ranked epilepsy fourth out of five, behind diabetes and chronic respiratory or cardiac problems. Only psychiatric problems ranked below epilepsy. In the workplace, negative attitudes towards PWE are also evident.[5; 47] Jacoby[5] reported that for employees, working with a PWE would cause great concern, second to working with a person suffering from stress or depression. Studies seemed to indicate that while the general population did not typically voice stigmatizing ideas or thoughts, their attitudes indicate recognition that stigma exists.[46–48]

1.4.3. General population sources of information on epilepsy—A number of studies assessed sources of information about epilepsy. Mass media appears a common source of information.[36; 49–51] However, reliance on mass media is not universal, as Degirmenci[46] reported that less than 20% of respondents (mostly adults) got information from television, radio, internet, brochures or newspapers and magazines.

Eight studies focused on the portrayal of epilepsy in the news media and social media.[52–59] Caspermeyer[58] reported that approximately 15% of stories about 11 different neurological conditions contained stigmatizing language. However, there was no breakdown by neurological disease and no specific examples given of stigmatizing language. Perhaps the most informative study was by McNeil[59] who performed a content analysis of Tweets containing the word "seizure*" over a 7-day period. Less than half of the Tweets contained information (12%), personal accounts (31%), and people seeking advice (2%). The other comments were categorized as ridicule and jokes (9%), metaphorical references to seizures (32%), opinions (6%), and miscellaneous comments (6%). Derogatory comments were present in 41% of over 5,000 tweets analyzed.

1.4.4. Variables associated with misconceptions and stigma—

Epilepsy stigma was most likely to occur in individuals with less education, lower socioeconomic status, minorities and those with no exposure to PWE.[19; 24; 40; 60; 61] Individuals at the more extreme younger or older age ranges also had more misconceptions.[19; 22; 60]

1.5. Interventions to reduce epilepsy stigma

Only 12 studies included an intervention (Table 2), and of these, only one was conducted in the United States.[62] The number of participants in studies varied widely, from 20 to over 1,300. Most studies (N=9)[26; 28; 51; 78; 79; 80; 81; 82; 84] were non-controlled prospective trials, three were randomized control trials.[34; 42; 83] Interventions targeted primary and elementary students[42; 51; 83] (N=3), high school students[34] (N=1) and college students[26; 28] (N=2) as well as school teachers[78; 79; 81; 84] (N=4) and health professionals[80; 82] (N=2). Consistent with the pedagogical and clinical settings, interventions relied on communicating health information via lectures or other formal, lengthy curricula to train or educate their target audiences. Studies presented factual information regarding management of seizures, implications of epilepsy, and first aid for someone who had a seizure via videos, lectures, and simulation to allow for cognitive shaping of attitudes. A combination lectures, courses, or seminars were mostly commonly used communication approaches[78; 79; 80; 81] (N=4). Combinations of seminars, lectures, trainings, and courses were all classified under the same approach because there were no distinguishing factors in the brief methods sections in these intervention papers. Another popular intervention strategy[28; 42; 83] (N=3) was an audio visual mixed modality that included discussion and/or role playing. Next, lecture only[82] (N=1) or lecture with discussion[51] (N=1) were used. Other strategies included simulation[34] (N=1), video only[26] (N=1), and education session with education kits[84] (N=1). Overall the studies noted an improvement in epilepsy knowledge and improved attitudes towards PWE.

In the literature on health communication strategies for epilepsy interventions, there was a focus on providing factual information/education. Outcomes suggested improved epilepsy knowledge and attitudes for various timeframes post-intervention (immediate to two years). However, these intervention studies did not assess whether this additional knowledge or change in attitude translated into measurable behavioral changes in real-world settings. Furthermore, how epilepsy stigma was addressed is not consistently obvious in the health communication interventions.

Discussion

Findings from this literature review on epilepsy stigma and stigma-reduction efforts suggests that although there is a substantial literature on misconceptions, negative attitudes, and stigma surrounding epilepsy from developing and non-Western countries, there is a relative paucity of recent information from the Americas, Europe and Australia, and a very limited literature on stigma-reduction strategies in these settings. Most of the literature relies on responses to the same kinds of questions from decades ago, which reflect what we would today consider unacceptable forms of negative attitudes, especially in our post-ADA society. Notably, we found relatively little utilization of qualitative methods to elicit new information that could then be used in innovative intervention programs. Key findings of this literature review and implications for future work are noted in Figure 3.

Key epilepsy misconception themes in the research literature over the past decade include limitations on normal social roles (socializing with PWE, marriage, children, employment), conditions associated with epilepsy (cognitive and behavioral difficulties and disabilities), personal characteristics of PWE (unreliable, dangerous), restrictions placed on activities (driving, sports), and inaccurate beliefs regarding the causes, treatment, and prognosis of epilepsy. Unfortunately, we could not compare the frequency and nature of misconceptions across population subgroups because of extensive variability in study design and methods.

Most published studies on epilepsy misconceptions and stigma used standardized instruments that relied upon closed-ended questions. Some epilepsy misconception questions in published reports were worded such that they invited over-generalization of items that can be true for some individuals and turned them into blanket statements about all PWE. For example, saying “epilepsy can kill” is an important message for PWE who are at risk of Sudden Unexpected Death in Epilepsy (SUDEP).[63] However, portraying epilepsy as a lethal condition is unlikely to reduce stigma. For example, one could imagine that employers might be less likely to hire PWE if they think a person can die while having a seizure at work. Although PWE can have a variety of cognitive difficulties, most of these are relatively subtle and can be managed with appropriate compensatory approaches. Few studies used open-ended or qualitative methods that might provide a finer-grained understanding of current misconceptions and stigma. To arrive at different answers, it is important to ask new questions.

In the Americas, Australia, and Europe only a dozen interventional studies have been reported over the past decade targeting the general population which does not have epilepsy. Although the interventions in the 12 studies examined in this review improved attitudes about epilepsy, interventions were limited to healthcare and education settings and were time intensive and impractical to implement for the broad population.

This review suggests that published evidence on ways to best reduce epilepsy stigma in the general population is extremely limited. Summary findings demonstrate that both epilepsy knowledge and epilepsy attitudes can be improved with directed effort. While nearly all interventions appeared effective in improving epilepsy knowledge and attitudes in their respective target population, interventions mainly were intended for use in classroom or healthcare settings and used didactic delivery approaches that would not be expected to be practical or scale-able for the general population. Most importantly, their enduring impact was not assessed.

Given the paucity of evidence-based epilepsy stigma-reduction interventions, it may be reasonable to look at other stigmatizing disorder as to how future research might be operationalized. A mental illness stigma intervention protocol [64] suggests anti-stigma interventions should examine the effect on stigma and discrimination of people with mental illness as well as their caregivers. A similar research protocol would be applicable for research on stigma among people with epilepsy.

In marked contrast to the limited number of published research studies that tested interventions to address epilepsy stigma, there has been extensive work, most notably conducted by advocacy groups such as the Epilepsy Foundation (EF) and government agencies such as the Centers for Disease Control and Prevention (CDC), to implement public awareness campaigns that broadly address epilepsy awareness [65; 66] and which are intended to improve understanding, promote social inclusion, and reduce stigma. Subsequent to our literature review, Price and colleagues published a comprehensive summary of multi-faceted public education awareness campaigns that have been implemented in the U.S. from 2001–2013.[65; 67] Targeted educational efforts by CDC and EF support groups such as school nurses, first responders, school staff, and adult day-care personnel.[68]

Consistent with recommendations by Corrigan[69] suggesting that stigma reduction is most likely to be effective when it is targeted toward specific populations, has local relevance, and uses people from the targeted population to deliver the message, the EF and CDC campaigns targeted important subgroups including Tweens, African-Americans, Hispanic-Americans and Asian-Americans using communication approaches that leveraged the strength of mass and social media and included multiple formats such as audio and video release, celebrity endorsement and community events. A key feature of the public campaigns implemented thus far is their extraordinary reach. For example, the “26 Days of Epilepsy Awareness and Action” campaign in 2012–213 was delivered to more than 3 million individuals, including 1.9 million Asian-Americans. However, an important limitation of these public awareness efforts is that impact data mainly consisted of process outcomes that provided information on reach or uptake of the information (number of website visits, attendance, etc.) rather than specific effects of these efforts on epilepsy misconceptions and stigma.[65]

Health communication approaches used in interventions identified in this review used mainly lectures and videos. However, information provided through these means does not extend beyond the audience directly receiving the information. Effective health communication approaches need to engage individuals and communities in formats that are easily accessible and ideally without cost. Mass and multi-media health information can be delivered and shared at a rapid pace and potentially a larger audience. Future efforts to specifically target and reduce epilepsy stigma will almost certainly need to use technology-based approaches such as social media which might be expected to appeal to younger audiences. Novel communication technologies, including social network sites, text messaging, podcasts, blogs, and videos uploaded by organizations and Internet users are all potentially fruitful areas of investigation.[70] The ease of user “sharing” of web-based content allows for the continual spread of information. Since none of the epilepsy intervention studies in this review used novel health communication mediums, these new mediums need to be tested.

In addition to the format of communication channels utilized, it is important to consider the message being communicated. Protest against stigma, which involves identifying instances of incorrect ideas or discrimination and speaking out against them, can result in worse discrimination because of the increased focus on instances where it occurs.[69] Additionally, both cognitive beliefs (what a person believes is true/not true about PWE) and emotional responses that include fears about safety or risk can influence intentions for behavior that may result in avoiding PWE. [71; 72] Decision Theory posits that people have difficulty refuting negative information. Instead, correct positive information should be provided. [73] As an example, the statement "people with epilepsy aren't stupid" plants the connection of epilepsy with stupidity in the listener's mind. A preferred approach is to remain positive and avoid negative connections such as the statement "Most people with epilepsy are bright, engaged, and living full lives." Emotions are potent drivers of decision-making[74; 75] and positive emotional content, such as health communication approaches that emphasize caring, inclusiveness and altruism are known to be effective in shaping attitudes. [76; 77]

Limitations

Our literature search was focused on studies published in 2004–2015. As with any search, we may not have identified all pertinent articles, and our search and review strategy may have introduced some bias. Furthermore, while we identified similar themes across studies, findings from non-U.S. studies might not generalize to the U.S. population. A limitation common to most of the studies we reviewed is "social desirability bias," meaning that respondents may provide answers that they feel are socially appropriate, but not necessarily reflective of true attitudes and behavior. This could explain some of the subtle discrepancies among answers within the same questionnaire, such as the fact that individuals endorsed having positive attitudes towards PWE, but would still not disclose having epilepsy if they themselves had epilepsy. There are only a limited number of epilepsy stigma-reduction interventions and the relatively narrow audience focus of the existing interventions limits an approximation of how they might perform in general population samples.

Conclusions

As our review findings illustrate, types of epilepsy misconceptions were similar in reports published over the last decade, although most referred to misconceptions that have already been previously described. While some factors associated with stigmatizing misconceptions are non-modifiable, having no familiarity or exposure to a PWE appears associated with more misconceptions and may be an avenue for intervention within specific subgroups. There are remarkably few published research studies which specifically tested epilepsy stigma-reduction efforts. Techniques that re-frame stigmatizing beliefs, create positive affective reactions and can be implemented on a broad and easily-accessible population-level should be incorporated into the next generation of approaches to reduce epilepsy stigma.

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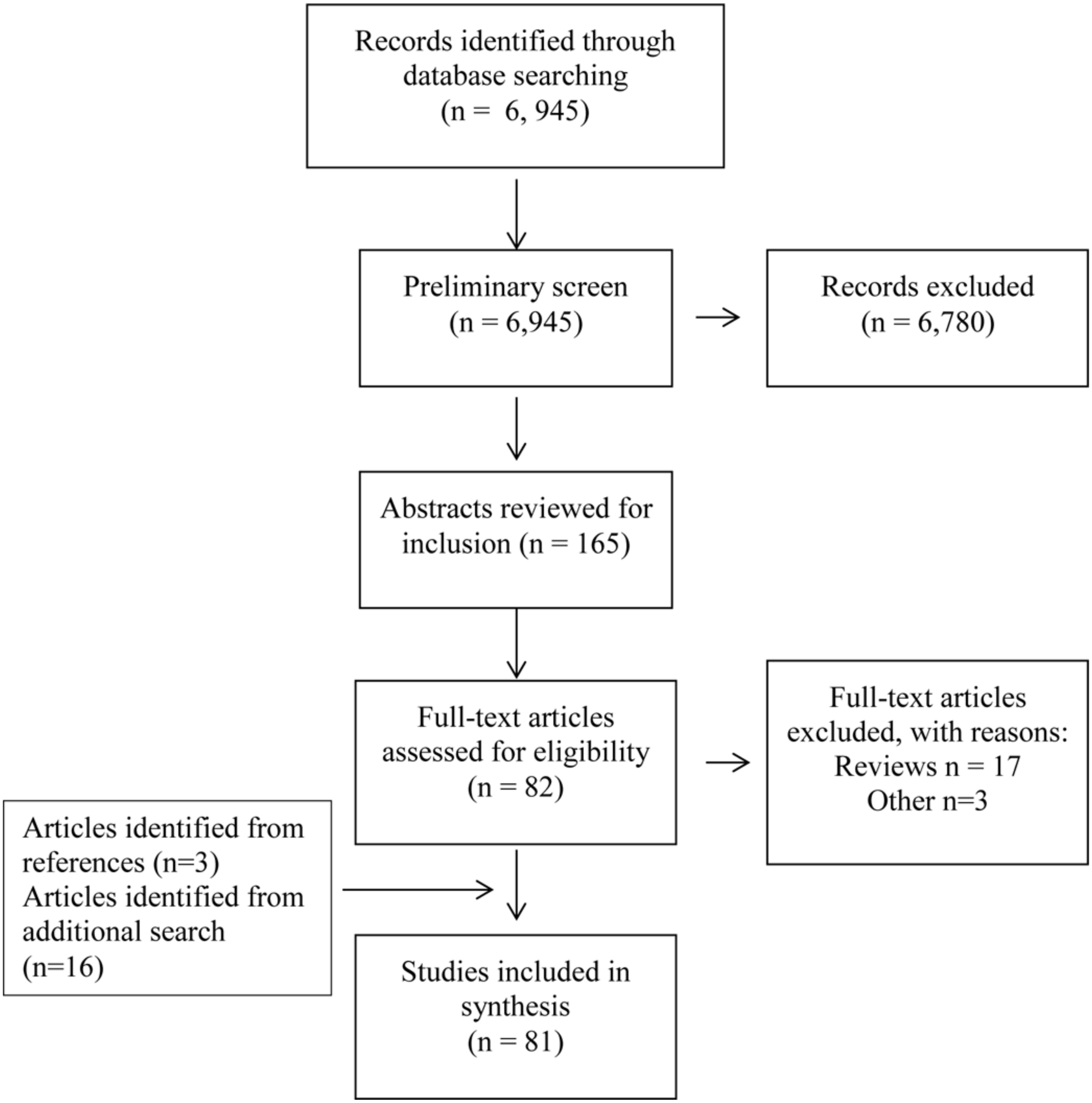


Figure 1: Literature Review Flow Diagram

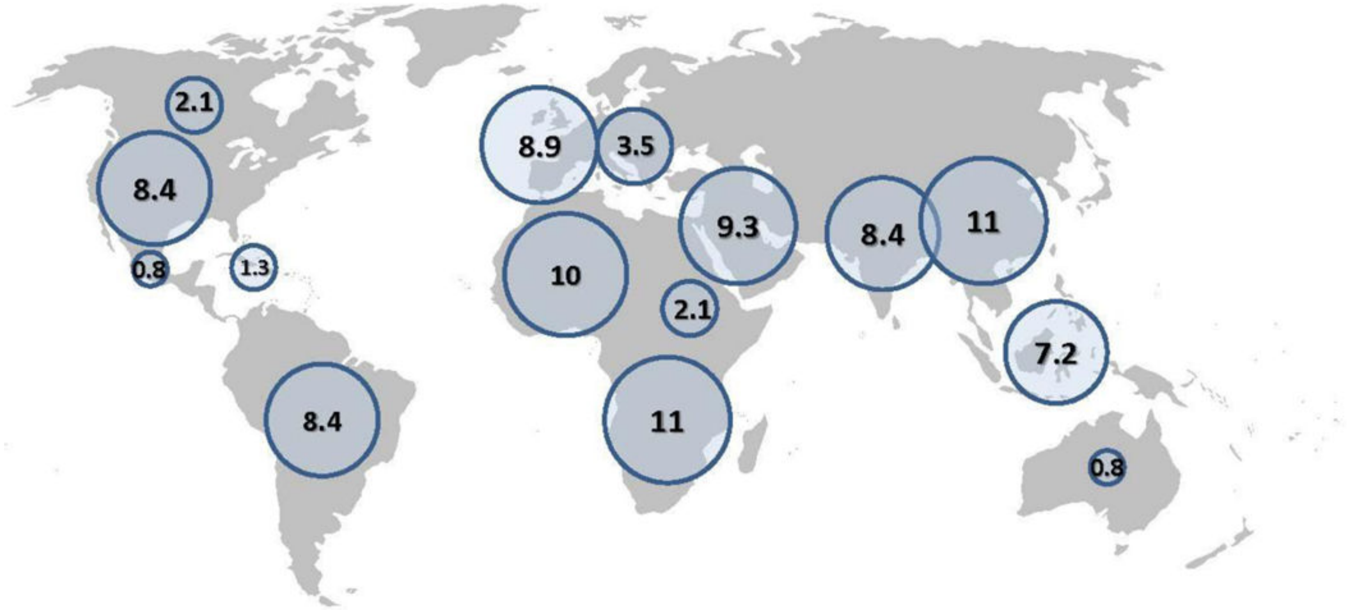
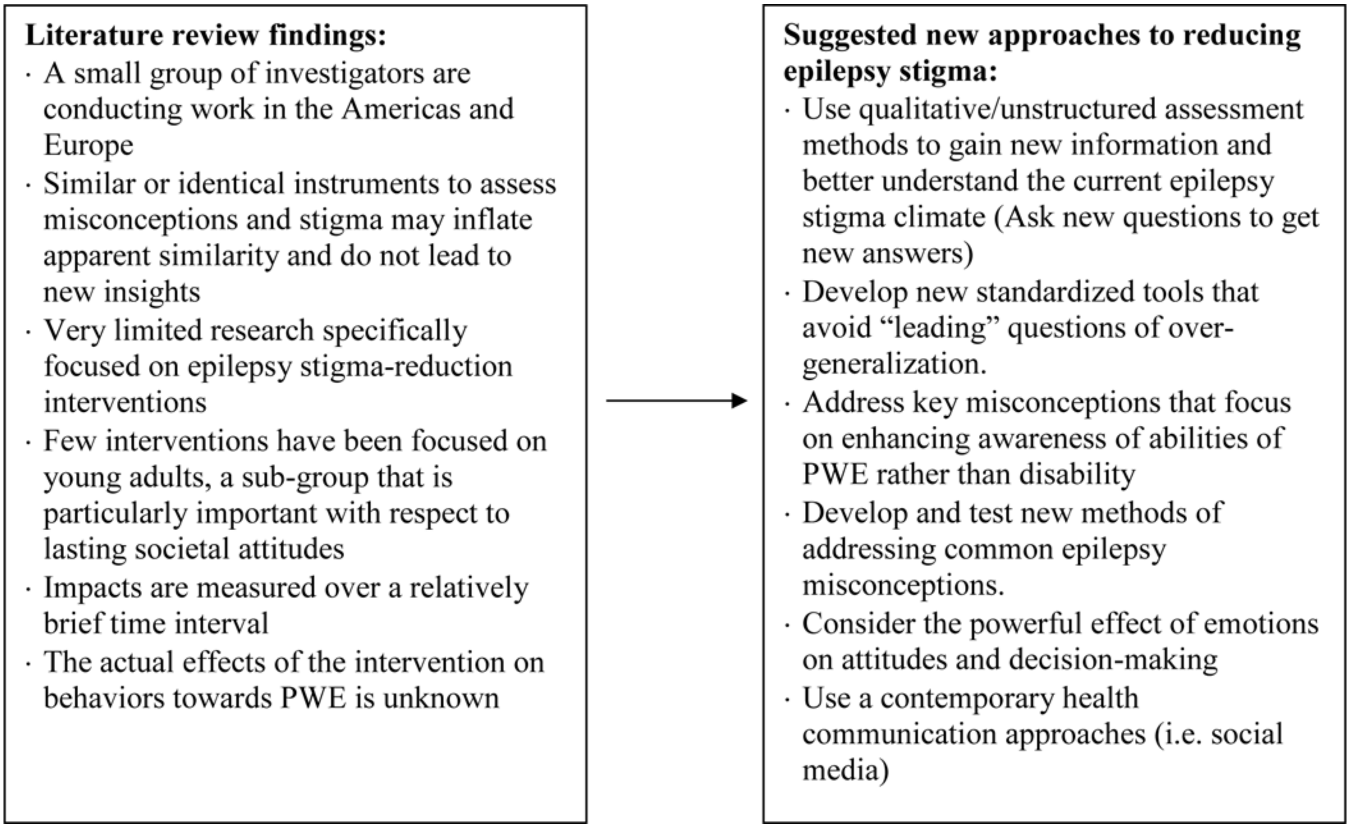


Figure 2: Map of Epilepsy Research January 2004 – 2015



Literature review findings:

- A small group of investigators are conducting work in the Americas and Europe
- Similar or identical instruments to assess misconceptions and stigma may inflate apparent similarity and do not lead to new insights
- Very limited research specifically focused on epilepsy stigma-reduction interventions
- Few interventions have been focused on young adults, a sub-group that is particularly important with respect to lasting societal attitudes
- Impacts are measured over a relatively brief time interval
- The actual effects of the intervention on behaviors towards PWE is unknown

Suggested new approaches to reducing epilepsy stigma:

- Use qualitative/unstructured assessment methods to gain new information and better understand the current epilepsy stigma climate (Ask new questions to get new answers)
- Develop new standardized tools that avoid "leading" questions of over-generalization.
- Address key misconceptions that focus on enhancing awareness of abilities of PWE rather than disability
- Develop and test new methods of addressing common epilepsy misconceptions.
- Consider the powerful effect of emotions on attitudes and decision-making
- Use a contemporary health communication approaches (i.e. social media)

Figure 3: Key findings and research implications from a synthesis of a systematized literature review on epilepsy stigma

Table 1:

Misconceptions categories identified in studies on epilepsy

	Examples
Social status / integration	Concern about socializing and befriending PWE Concern about close physical proximity (afraid to sit beside a PWE) PWE should be isolated PWE cannot have normal social roles / should not participate in social activities Objection to marriage for PWE Concern about PWE having children Concern about children with epilepsy associating with other children and attending regular school Concern that children with epilepsy may not succeed in life Perception that PWE may not be successful in specific professions Perception that epilepsy is more common in a lower socio-economic class / Religious people have lower risk of epilepsy PWE are responsible for their condition Idea that one can identify a PWE by appearance PWE may transmit the disease (i.e. epilepsy is contagious) PWE are a danger to the public Being a PWE is a disgraceful condition
Employment	Concern about hiring PWE Co-workers' concern about working with PWE Associate negative features to PWE as employees Concern for safety of PWE and others in the workplace
Associated Conditions (primarily cognitive and psychiatric)	PWE have poor cognitive capacity / lower IQ / are mentally retarded Children with epilepsy (CWE) almost always have mental or learning problems -and usually cannot be very good students PWE have impaired self-realization/lower self-confidence PWE have difficult personalities; aggressiveness, violence and behavioral disorders PWE have severe psychiatric disease PWE tend to develop and express criminal tendencies
Restrictions and limitations	PWE cannot work or number of suitable jobs for PWE is low PWE should not drive, operate heavy machinery PWE should not attend regular school PWE cannot participate in sports
Cause/nature of epilepsy	Excessive suffering in childhood Epilepsy is a blood disease / immune disease Epilepsy is a physical deficiency / sign of weakness Epilepsy is a form of madness or a mental disorder Epilepsy is caused by possession or a "spell" /supernatural disease/the devil/ moon cycles Epilepsy is punishment for past sins/past life PWE are fated by God to have epilepsy Is caused by bad thoughts, depression Epilepsy is a disease that can kill PWE have lower life expectancy
Treatment	PWE can be treated better in institutions Epilepsy drugs have to be taken for life Most PWE do not take epileptic drugs Epilepsy is not curable or controllable Treatments are teas and medicinal herbs Faith can heal epilepsy/ask for God's help/talismans/prayers Acupuncture Herbal medicine doctor/healer
First aid for seizures	Smelling something strong can end a seizure / spread vinegar or alcohol on patient's wrist PWE can swallow their tongue during a seizure, therefore try to pull out the tongue Place something between their teeth Hold the person down/try to contain, throw water at them Necessity for immediate medical intervention in the form of an ambulance crew to stop a seizure

Table 2:

Research studies testing an intervention intended to improve epilepsy misconceptions or stigma

Study	Country	Study Population & Design	Intervention Description	Health Communication Approach	Outcome Instrument and Results
Bekiroglu, Ozkan, et al. (2004)[78]	Turkey	Primary school teachers (N= 346) Prospective, uncontrolled trial	Seminars included 1. Four lectures about epilepsy causes and consequences as well as social, professional, and legal aspects of epilepsy 2. Training on attitude toward students with epilepsy and management of seizures. 3. Videos were used to show common types of epileptic seizures. Given by member of the Committee of Education of the Turkish League Against Epilepsy	Seminars that included lectures, trainings, and videos	Developed own questionnaire measuring attitude toward epilepsy Improved awareness, knowledge, and attitudes, decreased misperceptions Post-seminar survey, no follow up
Aydin, Yildiz (2007)[79]	Turkey	Primary public school teachers (N=275) Prospective, uncontrolled trial	45 minutes education program including a seminar on causes and consequences of epilepsy, social, professional, and legal implications of epilepsy, as well as instruction about attitudes toward students with epilepsy and first-aid management for seizures. Given by a pediatric neurologist	Education program including seminar and instructions	Developed own questionnaire measuring perception of epilepsy (knowledge, attitude, and practice) Improved knowledge and attitudes and a positive change in epilepsy perception at one month follow-up
Fernandes, Noronha, et al. (2007)[80]	Brazil	Physicians, health professionals (Module 1 N=194 in the pre-test, N= in both pre and post-test Module 2 N= 484 pre-test, 147 both pre and post-test) Prospective, uncontrolled trial	Training consisting of three separate modules for different health professionals: Module 1. 8 hour information courses for physicians Module 2. 3 hour course for health professionals and community leader Module 3. “Training the trainers” course for physicians to help them deliver information about epilepsy to other health care providers in their communities	Informational, multi-hour courses	Developed own questionnaire Improved knowledge, attitudes, and perceptions for both Modules 1 and 2 six months after courses
Fernandes, P. T., A. L. Noronha, et al. (2007)[81]	Brazil	Elementary education teachers (N=20, training course completers) Prospective, uncontrolled trial	20 hour training course “Epilepsy and Health” with 8 hours about epilepsy and 12 hours about educational methods to use in class on the theme of epilepsy.	Training course	Developed own questionnaire Improved knowledge, attitudes and perception at up to 2 years follow-up

Study	**Country**	**Study Population & Design**	**Intervention Description**	**Health Communication Approach**	**Outcome Instrument and Results**
Martiniuk, Speechley, et al. (2007)[42]	Canada	Grade 5 students (N=783) Cluster randomized, controlled trial, with schools as unit of randomization	A 30-minute 'Thinking about Epilepsy' educational program, using posters, photographs, a television commercial, a puppet show, and role playing	Posters, photos, television commercial, puppet show, role play	Developed own questionnaire Improved knowledge and attitudes at 1 month follow-up
Reno, Fernandes, et al. (2007)[34]	Brazil	Students of first year of high school (N= 182 pre/86 post) Randomized controlled trial	Two groups were shown a simulation of a tonic-clonic seizure: one group was shown how to respond correctly; another group was shown incorrect response. A third group was the control that did not see a simulation and received no information about epilepsy. All subjects completed a questionnaire.	Simulation	Used Stigma Scale of Epilepsy (SSE) plus three questions Improved attitudes in group given correct information
Smith, Siddarth, et al. (2007)[82]	US	Pediatric neurologists (N=18) Pediatricians (N=17) Prospective, uncontrolled trial	50 minute lecture on cognitive and behavioral impact of pediatric epilepsy as well as bio-psycho-social factors Information presented by a pediatric neuropsychiatrist with clinical and research experience in pediatric epilepsy	Lecture	Developed own questionnaire Improved knowledge about impact of epilepsy in children
Tedrus, Fonseca, et al. (2007)[28]	Brazil	University students in health sciences (N= 285 pre; N=116 post) Prospective, uncontrolled trial	2 hour presentation of audio-visual material about biological and psychosocial aspects of epilepsy, followed by a brief discussion. Audio-visual material produced by the Brazilian League of Epilepsy	Audio-visual material	Developed questionnaire based on Caveness and other surveys Improved knowledge and attitudes
Bozkaya, Arhan et al. (2010)[51]	Turkey	Primary school students (N=851) Prospective, uncontrolled trial	Lecture and discussion session presenting information on epilepsy. Educational strategies used included practice with a simulated patient, case-based discussion, and videos of seizures.	Lecture and discussion	Developed own questionnaire Improved knowledge and attitudes improved
Roberts, Farhana (2010)[26]	Australia	Undergraduate psychology students (N=131) Prospective, uncontrolled trial	10 minute informational first aid video including testimonials, based on previous educational videos and national guidelines. Development by the Epilepsy Tasmania Association	Video	Developed questionnaire based on Caveness and on DiIorio *(ABLE)* Improved knowledge and attitudes
Brabcova, Lovasova, et al. (2013)[83]	Czech Republic	Elementary school students (N=1,342)	20 minute video (group 1) or interactive drama (group 2) with a narrative approach where one main character had epilepsy.	Video and interactive drama with narrative approach	Developed own questionnaire Improved knowledge

Study	Country	Study Population & Design	Intervention Description	Health Communication Approach	Outcome Instrument and Results
		Randomized (school level), controlled trial	Control group with no intervention (group 3)		and attitudes in interventions compared to control
Mecarelli, Messina, et al. (2015)[84]	Italy	Primary school teachers (N= 582 pre; N=317 post) Prospective, uncontrolled trial	Education session on epilepsy. Educational kits to share with the students.	Education session and educational kits containing brochures, story (fairy tale), poster	Developed own questionnaire Improved knowledge but not attitudes