



## Review

# 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 were used for this review.

**Results:** Eighty-one 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 overgeneralizations 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 destigmatize epilepsy may help reduce misconceptions.

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## 1. 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 by 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

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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.

## 2. 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.

### 2.1. 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\*, and discrimination\*, with keyword 1: epilepsy or seizure\* and keyword 2: myth\* or misconception\* or stigma or bias or restriction\* or discrimination\*; (\*) was used as a 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 secondary keywords.

Another less detailed search was done using Web of Science using keywords 1 (epilepsy or seizure\*) 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.

#### 2.1.1. 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 nonrandomized 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 misconceptions from the group without epilepsy 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.

#### 2.1.2. 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 antistigma 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.

### 2.2. Selection of publications

All abstracts were prescreened 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.

#### 2.2.1. 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.

## 3. Results

### 3.1. 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 keyword epilepsy or seizure\* combined with any of the words stigma, myth\*, and 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 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 (Fig. 2). Some studies did not fall into a single region (N = 6) or were done based on online resources such as YouTube (N = 4). They are not plotted but were included in the denominator.

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