



## Review

# Correlates of perceived stigma for people living with epilepsy: A meta-analysis



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## ABSTRACT

**Objective:** Epilepsy, one of the most common, serious chronic neurological diseases, is accompanied by different levels of perceived stigma that affects people in almost all age groups. This stigma can negatively impact the physical and mental health of people living with epilepsy (PLWE). Good knowledge of perceived stigma for PLWE is important. In this study, we conducted a meta-analysis to identify the correlates of perceived stigma for PLWE.

**Methods:** Studies on factors associated with perceived stigma for PLWE, including sociodemographic, psychosocial, and disease-related variables, were searched in PubMed, PsychINFO, EMBASE, and Web of Science.

**Results:** Nineteen variables ( $k > 1$ ) were included in the meta-analysis. For sociodemographic characteristics, findings revealed that the significant weighted mean correlation (R) for “residence” and “poor financial status” were 0.177 and 0.286, respectively. For disease-related characteristics, all variables of significance, including “seizure severity,” “seizure frequency,” “number of medicines,” and “adverse event” (R ranging from 0.190 to 0.362), were positively correlated with perceived stigma. For psychosocial characteristics, “depression” and “anxiety” with R values of 0.414 and 0.369 were significantly associated with perceived stigma. In addition, “social support,” “quality of life (QOLIE-31,89),” “knowledge,” and “attitude,” with R values ranging from  $-0.444$  to  $-0.200$  indicating negative correlation with perceived stigma.

**Conclusion:** The current meta-analysis evaluated the correlates of perceived stigma for PLWE. Results can serve as a basis for policymakers and healthcare professionals for formulating health promotion and prevention strategies.

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## 1. Introduction

Epilepsy is one of the most common, serious chronic neurological diseases and affects people in all age groups worldwide. According to a WHO report, more than 50 million people around the world suffer from epilepsy, three-quarters of whom live in low- and middle-income countries. An estimated 2.4 million new cases are discovered every year, accounting for 0.5% of the global burden of disease [1].

Epilepsy sufferers are often stigmatized in view of the misconceptions and negative attitudes surrounding the disease, including evil possession or equating the disease to mental instability. The concept of such stigma dates back to Goffman's book *Stigma: Notes on the Management of Spoiled Identity*. In this book, he referred to stigma as “an attribute that is deeply discrediting.” Since then, the definition of stigma has diversified and the content became abundant. Some researchers have concluded that stigma for patients is categorized in three main ways: experienced (or enacted stigma, experience of actual discrimination), self-stigma (or internalized

stigma, feelings of loss of self-esteem, fear, shame, and other negative emotional experiences), and perceived stigma (or felt stigma, which refers to the extent that patients feel discrimination even though stigma is actually not overtly present) [2,3].

Prior research regarding people living with epilepsy (PLWE) pointed out that the perceived stigma imposes a burden onto patients and has many effects, such as negatively compromising the psychological health, quality of life, and well-being of PLWE [4–6]. Specifically, epilepsy-related perceived stigma is associated with stress [7], depression and anxiety [8–10], reduced self-esteem [9], reduced self-efficacy [11,12], poor medication adherence [11], and more adverse events of antiepileptic drugs [13,14].

Appropriate measures should be applied to deal with epilepsy-related perceived stigma and improve the quality of life and health of PLWE. These measures must consider those factors contributing to perceived stigma. To date, a number of qualitative and quantitative studies has investigated the correlates of perceived stigma for PLWE. However, a great variability was found in the reported findings regarding the relationships between perceived stigma for PLWE and other characteristics of interest, such as gender, age, and depression. Additionally, the findings related to perceived stigma for PLWE have not yet been reviewed in a comprehensive or systematic manner. Hence, the present study

Abbreviations: PLWE, people living with epilepsy; QOL, quality of life; OR, odds ratio; FSN, fail-safe number.

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represents the first meta-analysis of correlates relating specifically to perceived stigma for PLWE by evaluating sociodemographic, psychosocial, and disease-related variables purported to have a statistical relationship with perceived stigma for PLWE according to quantitative studies. Our findings can serve as basis for policymakers and healthcare professionals in establishing health promotion and prevention strategies.

## 2. Methods

### 2.1. Search strategy

We performed systematic searches in PubMed, PsychINFO, EMBASE, and Web of Science. Web of Science includes the Arts & Humanities Citation Index, the Social Citation Index, and the Social Sciences Citation Index. Retrieval time limit was until 21 November 2016. Search strategies that used terms specifically embedded in each database were purposely selected to maximize sensitivity (see Supplemental data S1 for search strategies). Additional articles were retrieved by manually searching the references of all selected full-text articles.

### 2.2. Eligibility criteria

Articles that satisfied the following criteria were included in the meta-analysis: (i) constitutes primary research published in a scholarly or professional journal; (ii) includes a sample of people diagnosed with epilepsy; (iii) includes independent quantitative measures regarding perceived stigma or felt stigma and at least another variable (such as demographic variable); (iv) reports the statistical relationship between two variables using Pearson or Spearman correlation  $r$  or crude OR; (v) can be retrieved by contacting the author or through university library services; and (vi) is written in English.

### 2.3. Study selection

We followed PRISMA guidelines in conducting this meta-analysis [15]. We first imported all records into EndNote X7 reference management software and used the automated “Find Duplicates” function to exclude any duplicates. We then screened the titles and abstracts of all records to identify the studies that appeared as potentially related to stigma among people with epilepsy. We finally obtained the full text of these articles for review and identified the studies that satisfied the above eligibility criteria.

### 2.4. Quality assessment

The reviewers (Y.S. and S.Q.) independently assessed the methodological quality of each selected article with a method adapted from the Depression in Epilepsy Quality Assessment Tool [16]. One item was skipped because the use of multivariate analysis was inapplicable. Six items were finally included: prospective study design, response rate greater than 60%, consecutive or random sample, sample size greater than 115, validated method of epilepsy diagnosis, and independent stigma identification. If a study met any of these criteria, then one point was awarded to this specific study. Studies with scores above the median were classified as high-quality studies [17].

### 2.5. Data extraction

Two authors (M.L. and J.Y.) performed the data extraction using a designed form. From each included study, the following data were extracted: authors and year of publication; study design; sample of the study population; quantitative measures regarding perceived stigma or felt stigma for PLWE; assessed sociodemographic, psychological, social, and disease-related variables; and the reported effect size. The total score was obtained with a score of each subscale and a total score

(e.g., QOL). This method was consistent with that used by Logie and Gadalla in an AIDS internalized stigma meta-analysis [18]. If the score was the score of subscale rather than the total score, then the variable was excluded. In addition, if a variable was evaluated more than once (e.g., repeated measurements at different time points or with different evaluation tools to evaluate the same variable), then the median of each effect value was obtained. If the variable had only two values, then the lower value was used [19].

### 2.6. Data analysis

Data extracted were encoded into the Comprehensive Meta-analysis Version 2 software program for calculation of weighted mean correlation ( $R$ ) for each variable. Pearson and Spearman correlation coefficients ( $r$ ) were used as the effect size for the analyses. When the odd ratio (OR) was reported instead of the correlation coefficient, CMA converted the crude OR into correlation coefficient. Only bivariate or univariate analyses were synthesized because multivariate analyses cannot be compared between studies since the studies adjust for different confounders in their models. Meta-analysis was performed only with the data of two or more independent correlations ( $k > 1$ ).

Random effects models were selected according to the possible heterogeneity of the sample groups and the methodological characteristics of the included studies.  $Q$  statistic and  $I^2$  index were used to determine the homogeneity of correlations across the studies. The researchers used  $Q$  to examine the degree of heterogeneity, and  $I^2$  was used to describe the proportion of the variance in the total variance of the study population: 25% is low heterogeneity, 50% is moderate heterogeneity, and 75% is high heterogeneity [20].

Publication bias test was used to determine the degree of publication bias of the meta-analysis by calculating the Rosenthal's fail-safe number (FSN). A larger FSN value indicated a more robust weighted mean effect size. According to the meta-analysis of Scheermet al., recommended tolerance is  $5k + 10$ , where  $k$  is the number of studies retrieved. The FSN is calculated only when  $k > 2$ . If the FSN value is larger than the recommended tolerance, then the results are robust [21].

## 3. Results

### 3.1. Study selection

The search strategies identified 2395 publications; 1627 studies remained after removing the duplicates. Screening of the title and abstract led to retention of 145 potentially relevant articles. Full-text reading resulted in exclusion of 117 publications. One full-text article was found in snowball. Ultimately, 29 studies were identified for inclusion in this review [4,5,7,10–12,14,22–43]. The flow diagram displays a summary of the excluded papers and the reason for their exclusion (Fig. 1).

### 3.2. Study characteristics

Supplemental data S2 presents the characteristics and cumulative score of the quality assessment of included studies for the meta-analysis. Only three prospective studies were included. For cross-sectional studies, the quality assessment scores ranged from one to five points. Prospective studies scores ranged from four to six points.

### 3.3. Synthesis of results

The results of meta-analysis and heterogeneity analysis for the correlates of stigma are presented in Tables 1–3. The majority of heterogeneity tests were significant. The  $k$  of the correlation coefficient must be over 2; hence, 19 variables were used for the meta-analysis, including sociodemographic characteristics (age, gender, residence, and financial status), disease-related characteristics (seizure severity, disease duration, seizure frequency, medication adherence, number of medicines, age

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