Perceived Stigma in Epilepsy Patients in a Low Income Country; Ethiopia: A Review and Meta-Analysis of the Prevalence and Related Factors.

Mogesie Necho (nechomoges2014@gmail.com)
Wollo University
https://orcid.org/0000-0003-2157-1147

Mengesha Birkie
Wollo University

Sisay Gedamu
Wollo University

Tefsaye Birhan
Wollo University

Research

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Abstract

Background: The presence of perceived stigma hinders epilepsy patients from help-seeking behavior and diminishes adherence to medical follow-up. Despite this, the limitation of aggregate evidence regarding the prevalence and associated factors of perceived stigma existed in Ethiopia.

Methods: Our search for eligible articles was accompanied in the databases of PubMed, Scopus, EMBASE, and African Index Medicus. An additional manual search by the enumeration of the reference list of other articles was done. We used stata-11 and random-effects models to obtain the average prevalence of perceived stigma. Heterogeneity was assured with the Higgins I^2 test and Cochran’s Q-statistic. Sensitivity analysis and sub-grouping analyses were done. Qualitative checks for symmetry in funnel plot and quantitative description of Egger's test were done to check a publication bias.

Results: Of 1524 articles identified by the electronic and manual search, only 10 articles fulfilled the eligibility criteria and included in the analysis. The average prevalence of perceived stigma was found to be 43.79% (95% CI: 31.84, 55.75). The prevalence of perceived stigma varies across the measurement tool used, study location, and year of publication. The average prevalence of perceived stigma in studies measured with the modified FIS scale was 76.3%; higher than those studies measured with the Kilifi stigma scale; 33.63% and three-item stigma scale; 39.5%. Besides, the average prevalence of stigma was higher in Amhara (53.2%) and the Oromia region (52.2%). Studies published before 2016 provide higher perceived stigma (56.26%) than studies published after 2016 (35.47%). Our qualitative analysis revealed that rural residence, low level of education and income, age groups of 18 to 24 years, frequent seizure occurrence, contagion believe regarding epilepsy, duration of epilepsy from 1-10 years, depression and anxiety co-morbidity were among the associated factors with perceived stigma in people with epilepsy.

Conclusion: The average prevalence of perceived stigma in people with epilepsy was high and varies across study location, measurement tool, and study's publication year. Management of epilepsy should focus on the stigma component besides the biological intervention.

Background

Epilepsy is a neurological disorder characterized by a frequent imbalance of the nervous system secondary to the excessive hyper synchronous discharge of neurons that affects consciousness and sensation. Globally more than 70 million individuals are affected by epilepsy (1). More than three fourth (80%) of epilepsy case resides in the low and middle-income countries (LMIC), and brought tremendous complications in terms of social, health, psychological, economic and cultural effects (2, 3). In developing nations, the most reported commonness of active epilepsy varies from 5 to 10 people per/1,000 population, and this is more predominant in rural communities (4, 5). In Africa, the prevalence of epilepsy ranges from 2.2 to 58 per 1000 individuals (6). In Ethiopia too, epilepsy is a significant public health problem with a burden of 29.5 per 1000 population (7).

Stigma is an “attribute that is extremely disputing” and diminishes the individual who endures it “from a whole normal individual and to a spoiled, discounted” (8). Link and Phelan (9) redefine stigma as the co-incident of “stereotyping, labeling, separation, discrimination, and status loss. Stigma can be a public stigma in which nearby people prejudice and discriminate against people living with epilepsy (10). On the other hand personal stigma refers to the experience of stigma by oneself or self-stigma and perceived stigma. In this case epilepsy patients have a mindset or perception that the general public has a stigmatizing attitude towards their illness towards their condition (11). Finally, the acceptance of stereotypic views of public stigma by the individual with epilepsy is referred to as internalized/ self-stigma (12). In short, self-stigma is defined as the identity transformation from a previously held positive believes towards oneself to predominantly negative beliefs, self-esteem, and efficacy, and attitude (13). In the present review and meta-analysis study, we focused completely on articles comprehending data on the prevalence and associated factors of perceived stigma in epilepsy patients.

Multiple studies in the developed world reported the negative impacts of stigma in people with epilepsy in the psychological, social, and physical domains (14, 15). Such studies had reported that problems in social relationships, negative self-esteem and self-efficacy, help-seeking difficulties, unemployment, and homelessness are among the impacts of perceived stigma (16–20).

A study by Shibire et al.2006 (20) in Ethiopia showed that 60% of people living with epilepsy were facing psychological, physical, and social problems due to their illness. In this same study, 24% of patients were being stigmatized, 9% were suffering from serious physical injuries, 17% were not able to attend their education, 9% of patients were unemployed due to the illness, 10% had sustained a burn accident and 31% have faced a difficulty to find a partner (21).

Consequently, individuals living with epilepsy perceived their illness as stigmatizing and multiple studies showed that the prevalence of perceived stigma in epilepsy varies in different countries. For instance, a European study that involves 5000 patients with epilepsy across 15 European countries reported that 51% of people with epilepsy were having perceived stigma (14). Similarly, a case-control study piloted in Cambodia reported that 46% of people with epilepsy were living with perceived stigma (22). Based on a report from a cross-sectional at Brooklyn Hospital Academic Medical Center, 69% of people with epilepsy had perceived stigma (23). Other earlier studies reported that the prevalence of perceived stigma in people living with epilepsy was 33% in Iran (24), 68.7% in Benin (19), and 33% in Kenya (25). In the case of Ethiopia, the prevalence of perceived stigma among people living with epilepsy ranges from 31.1–81% (20, 26–34).
A review study in Asia reported that rural residence, lower-income, and education, being female, not witnessing individuals having the disorder, contagious belief regarding epilepsy and mental illness co-morbidity were among the associated factors with perceived stigma (35, 36). In another review of literature in Nigeria, the psychopathology associated with epilepsy is the main factor for perceived stigma in people with epilepsy (37). In Ethiopia too rural residence, poor income and education, young age, frequent seizure occurrence, contagion believe regarding epilepsy, longer duration of epilepsy, and presence of psychopathology was associated with perceived stigma (20, 27, 29, 32, 33).

The World Health Organization (WHO) has designed a Global Campaign against Epilepsy and its related stigma entitled "Out of the Shadows" initiative (38) so that the larger and wider population should stand against epilepsy and the related stigma. In Ethiopia however, there is a limitation of evidence on perceived stigma in people with epilepsy. Even, the little evidence obtained regarding perceived stigma is from cross-sectional studies that might not be strong evidence for policy recommendation. Therefore, looking for aggregate evidence on the prevalence and the associated factors of perceived stigma in people with epilepsy are significant and confidently useful for the design of programs for the management of perceived stigma and minimize the negative consequences. Thus, this meta-analysis study was conducted to (1) determine the average prevalence of perceived stigma in people with epilepsy in Ethiopia and (2) provide a narrative synthesis regarding the associated factors for perceived stigma in Ethiopia.

**Methods**

The Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols (PRISMA-P) guideline (39) was used as a reference during the study process.

**Search strategy**

We applied both an electronic as well as manual assessment for eligible articles. The search databases addressed in the electronic search were Scopus, PubMed, and EMBASE and African Index Medicus. These databases were explored for the existence of evidence on the subject of perceived stigma AND/OR associated factors for people living with epilepsy. Our search in the pub-med database was applied exhausting the keywords and headings of (prevalence OR Epidemiology OR Incidence OR Magnitude AND "stigma" OR perceived stigma AND epilepsy OR epileptic OR seizure OR seizure disorder AND "risk factor" OR determinant OR factor OR associated factors AND Ethiopia). The above search strategy was developed considering the PICO organization; extended using the MeSH terms and finally joined one another with the Boolean operators. The electronic search for data in EMBASE, Psych-Info, African Index Medicus, and Scopus was also accompanied in line with database-specific searching strategies. A manual search for the reference lists of the included studies was also done. Grey literature was also addressed over the mentioned search databases and Google scholar. During the search process, we did not put time restrictions on the inclusion of articles.

**Eligibility criteria's**

We included articles published in the English language, focused on determining the prevalence of perceived stigma AND/OR the associated factors in people with epilepsy. Articles included were also expected to be conducted in the context of Ethiopia and must be case-control, cohort, and cross-sectional in design. But by chance, all of the included studies were found to be cross-sectional. The studies included must also be conducted in adulthood population with an age of 18 years and above. We did not limit the year of publications of articles during our search procedure. We excluded earlier reviews and meta-analysis studies, studies in which the subjects were not human, editorials, and articles published in a language other than the English language. We performed our search in May 2020 and the search result was exported and stored in the endnote reference manager. Then the removal of duplication articles was done. Next to this, MN and MB independently screened the titles and abstracts of articles stored using the above-mentioned eligibility criteria. Again, these authors read the full text of the articles that were not excluded in the first step and independently decided on the articles that had to be included for final meta-analysis. Any variances in the notion concerning eligibility criteria between the above review authors were resolved by agreement and communication with the final reviewer (SG).

**Data extraction and quality assessment**

After deciding the articles to be included in the study, MN and MB extracted the essential data from the 10 included articles in line with a well-developed, standardized data extraction template organized as suggested by PRISMA guidelines (39). The components of the data extraction template were author and year of the study, location of the study, sample size, study design, outcome variable, target population, measurement tool used, response rate, and sampling techniques used in the study. Using these templates the data was extracted from included studies and summarized in the form of a table. The modified Newcastle–Ottawa Scale (NOS) (40) had been used for the quality appraisal of included studies. Statistical quality, ascertainment of cases representativeness of the sample, and comparability between participants were the dimensions of the NOS scale.

**Data synthesis and analysis**

The average prevalence of perceived stigma in people with epilepsy with its 95% CI was computed with Meta-XL version 5.3 (41) and Stata-11 Meta-prop package (42). The Cochran Q-statistics and Higgs $I^2$ statistics (43) were employed and interpreted to identify the between-study variance. The Higgs $I^2$ value of 50% and above during analysis indicates the existence of potential heterogeneity (43). In the present meta-analysis,
we obtained a significant difference between the included studies. Therefore, it was necessary to mitigate the source of heterogeneity. Likewise, we did a subgrouping analysis based on the regional location of the study, year of publication, and the measurement tools used to quantify perceived stigma. Further screening for a single influential study was also performed by leaving a single study out from the analysis at a time. We did also a screening for the presence of publication bias in the current study using a qualitative eyeball test (44) and quantitatively using the Eggers publication bias test. In this meta-analysis study a P-value < 0.05 was interpreted as statistically significant value.

Results

Identification of studies

Our systematic electronic as well as manual investigation for articles regarding the prevalence AND/OR associated factors of perceived stigma yields a total of 1524 articles. However, only 10 of the studies have been included in the final analysis after the remaining 1514 articles were excluded at the different stages of screening (Fig. 1).

Characteristics of included studies

Our screening for eligible articles resulted in 10 studies (20, 26–34), that assessed perceived stigma AND/OR the associated factors among 4016 people with epilepsy in the context of Ethiopia. All of the 10 studies were cross-sectional studies published between 2009 and 2018. Of these studies, three were conducted in Addis Ababa (28, 29, 32); the capital city of Ethiopia, another three were from Oromia regional state (20, 33, 34), two from Amhara regional state(27, 30) and the remaining two from southern Ethiopia (SNNP) (26, 31).

Considering the measurement tool, one study used Jacoby stigma scale(32), two studies used modified Family Interview Schedule (FIS) (20, 27), another two used three-item stigma scales (28, 34), and four utilized Kilifi stigma scale (29–31, 33) to measure perceived stigma in people with epilepsy. However, the assessment tool was not specified in one of the included studies. Among studies included; three (20, 26, 28) have no report regarding the response rate of the study participants. Eight of the included studies (27–34) used a systematic sampling technique and one study implemented a simple random sampling (26) and no sampling technique was reported in the remaining one study(20) (Table 1).
### Table 1
Characteristics of studies on perceived stigma among epilepsy patients included in the meta-analysis

| Author, year | Location | Study design | Sample size | Measurement tool used | Study population | Outcome variables | Perceived stigma (%) | Cases with stigma (n) | Response rate (%) | Sampling technique |
|--------------|----------|--------------|-------------|-----------------------|------------------|-------------------|----------------------|----------------------|-------------------|--------------------|
| Tegegne, 2016 (1) | Addis Ababa | CS | 415 | Jacoby stigma scale | People with epilepsy | Perceived stigma | 40.7% | 169 | 98% | Systematic |
| BB Biftu et al 2015 (2) | Amhara region | CS | 408 | Modified FIS | People with epilepsy | Perceived stigma | 71.6% | 292 | 96.7% | Systematic |
| Fata et al. 2015 (3) | Addis Ababa | CS | 346 | Kilifi stigma scale | People with epilepsy | Perceived stigma | 31.2% | 108 | 99.7% | Systematic |
| Tiki et al. 2018 (4) | Oromia region | CS | 335 | Kilifi stigma scale | People with epilepsy | Perceived stigma | 34.4% | 115 | 97.8% | Systematic |
| Shibire et al. 2006 (5) | Oromia region | CS | 831 | Modified FIS | People with epilepsy | Perceived stigma | 81% | 673 | NA | NA |
| Chaka et al. 2018 (6) | Addis Ababa | CS | 422 | Three item stigma scale | People with epilepsy | Perceived stigma | 37.7% | 159 | NA | Systematic |
| Angelo et al. 2018 (7) | SNNP | CS | 244 | NA | People with epilepsy | Perceived stigma | 31.1% | 76 | NA | Simple random |
| Tsegabirha et al. 2014 (8) | Oromia region | CS | 300 | Three item stigma scale | People with epilepsy | Perceived stigma | 41.3% | 124 | 100% | Systematic |
| Getinet et al. 2016 (9) | Amhara region | CS | 450 | Kilifi stigma scale | People with epilepsy | Perceived stigma | 34.9% | 157 | 98.04% | Systematic |
| M Shegaw 2017 (10) | SNNP | CS | 265 | Kilifi stigma scale | People with epilepsy | Perceived stigma | 34% | 90 | 100% | Systematic |

**Key:** CS: Cross-sectional, FIS: Family Interview Schedule, NA: Not available, SNNP: Southern Nations Nationalities and Peoples

### Quality of Included Studies

Overall, the quality score of the 10 included studies ranges from 6 (26) to 10 (27). There of the included studies (26, 29, 33) had moderate quality, and the remaining six of the included studies (20, 27, 28, 30–32, 34) had a good quality score. A study with poor quality was not present in this study (Additional file 1).

### The average prevalence of perceived stigma in people living with epilepsy in Ethiopia

Ten cross-sectional studies (20, 26–34) that reported the prevalence of perceived stigma in people with epilepsy in Ethiopia were included in the current meta-analysis. The stated prevalence of perceived stigma among the included studies ranges from 31.1% in SNNP (26) to 81% in the Oromia region (20). The average estimated prevalence of perceived stigma among people with epilepsy in Ethiopia was 43.79% (95% CI: 31.84, 55.75). This average prevalence was subjected to a high degree of heterogeneity ($I^2 = 99\%$, p-value $< 0.001$) from the difference between the involved studies (Fig. 2).

### The prevalence of perceived stigma in people with epilepsy in Ethiopia based on the measurement tool, the regional setting of the study, and the year of publication

Since the present meta-analysis study was with potential heterogeneity from the difference between included studies, our next step was performing a subgroup analysis to obtain the source for between-study differences. Therefore, we accomplished a subgroup analysis centered on measurement tools utilized to screen perceived stigma, study location, and year of publication of the studies.

### Subgroup analysis based on the measurement tool used to screen perceived stigma
Our sub-group analysis with measurement tool used to screen perceived stigma among patients with epilepsy revealed that the average prevalence of perceived stigma in studies that screened perceived stigma with modified FIS scale (20, 27) was 76.3% (95% CI: 67.8, 85.67) ($I^2$ = 98%, p-value < 0.001). This was significantly higher than the average perceived stigma of studies measured with Kilifi stigma scale (29–31, 33); 33.63% (95% CI: 31.98, 35.67) ($I^2$ = 94.6%, p-value < 0.001) and three item stigma scale (28, 34); 39.5% (95% CI: 35.97, 43.03) ($I^2$ = 96.8%, p-value < 0.001) (Fig. 3).

Subgroup analysis based on the regional setting where the study was conducted

Further exploration of subgroup based on region where the study was done implied that the pooled prevalence of perceived epilepsy stigma was much higher in studies from Amhara region (27, 30); 53.2% (95% CI: 17.34, 89.45) ($I^2$ = 96%, p-value < 0.001) and Oromia region (20, 33, 34); 52.2% (95% CI: 21.21, 89.46) ($I^2$ = 95%, p-value < 0.001) than the pooled prevalence of perceived epilepsy stigma in Addis Ababa (28, 29, 32); 36.5% (95% CI: 31.27, 52.38) ($I^2$ = 94.8%, p-value < 0.001) and SNNP (26, 31); 35.55% (95% CI: 29.71, 35.39) ($I^2$ = 94%, p-value < 0.001) (Table 2).

Table 2

| Associated factors                                      | Odds ratio(AOR) | 95% CI            | Strength of association | Author, year of publication |
|---------------------------------------------------------|-----------------|-------------------|-------------------------|-----------------------------|
| Being divorced/widowed                                  | 5.38            | 1.28, 22.62       | Strong and positive     | Tegegne,2016 (1)            |
| Rural residence                                         | 1.83            | 1.01, 3.33        | Moderate and positive   | Tegegne,2016 (1)            |
| Low income                                              | 2.4             | 1.26, 4.67        | Moderate and positive   | Tegegne,2016 (1)            |
| Frequent seizure                                        | 1.84            | 1.10, 3.07        | Moderate and positive   | Tegegne,2016 (1)            |
| Duration 2 up to 5 years                                | 4.38            | 1.98, 9.62        | Strong and positive     | BB Biftu et al 2015 (2)     |
| Duration 6 up to 10 years                               | 4.29            | 1.90, 9.64        | Strong, positive        | BB Biftu et al 2015 (2)     |
| Duration ≥ 11 years                                     | 4.3             | 1.84, 10.00       | Strong and positive     | BB Biftu et al 2015 (2)     |
| Frequency of seizure; 1 up to 11 per year               | 2.34            | 2.21, 3.56        | Moderate and positive   | BB Biftu et al 2015 (2)     |
| Frequency of seizure ≥ 11 per year                      | 5.63            | 3.42, 10.32       | Strong and positive     | BB Biftu et al 2015 (2)     |
| 18 to 24 age groups                                     | 2.84            | 1.02, 7.92        | Moderate and positive   | Fanta et al.2015 (3)        |
| Difficulty to attend follow up due to stigma            | 3.15            | 1.19, 8.34        | Strong and positive     | Fanta et al.2015 (3)        |
| Seizure related Injury                                  | 1.88            | 1.12, 3.15        | Moderate and positive   | Fanta et al.2015 (3)        |
| Contagion believe                                       | 1.88            | 1.12, 5.08        | Moderate and positive   | Fanta et al.2015 (3)        |
| No formal education                                     | 8.8             | 2.29, 33.82       | Strong and positive     | Tiki et al.2018 (4)         |
| Grad 1–8                                                | 6               | 2.05, 17.97       | Strong and positive     | Tiki et al.2018 (4)         |
| Duration of illness < 1 year                            | 5.66            | 2.09, 15.38       | Strong and positive     | Tiki et al.2018 (4)         |
| Duration of illness 2 to 5 years                        | 4.88            | 2.09, 11.33       | Strong and positive     | Tiki et al.2018 (4)         |
| Duration of illness 6 to 10 years                       | 3.7             | 1.55, 8.87        | Strong and positive     | Tiki et al.2018 (4)         |
| Depression co-morbidity                                 | 29.66           | 12.55,70.09       | Strong and positive     | Tiki et al.2018 (4)         |
| Anxiety co-morbidity                                    | 2.44            | 1.23, 4.84        | Moderate and positive   | Tiki et al.2018 (4)         |

Subgroup analysis based on the year of publications of the included studies

We also did a sub-group analysis on the ground of year of publication of the included studies. The result showed us that studies published before 2016 (20, 27, 29, 34); provide higher average prevalence of perceived stigma (56.26% (95% CI: 32.51, 80.04) ($I^2$ = 96.2%, p-value < 0.001)) than studies published in and after 2016 (26, 28, 30–33), 35.47% (95% CI: 32.85, 38.09) ($I^2$ = 94.5%, p-value < 0.001) (Table 3).
Table 3
A subgroup analysis of the prevalence of perceived stigma among epilepsy patients in Ethiopia with its 95% confidence interval

| Subgroup               | Number of studies | Estimates | Heterogeneity |  |
|-----------------------|-------------------|-----------|---------------|---|
|                       |                   | Prevalence (%) | 95% CI        |  |
|                       |                   |             |                |  |
| Study location        |                   |             |                |  |
| Addis Ababa (1, 3, 6) | 3                 | 36.5       | 31.27, 52.38  | 94.8% 165.27(2) P < 0.001 |
| Amhara region (2, 9)  | 2                 | 53.2       | 17.34, 89.45  | 96% 284.3(1) P < 0.001 |
| Oromia region (4, 5, 8)| 3                 | 52.2       | 21.21, 89.46  | 95% 217.8(2) P < 0.001 |
| SNNP (7, 10)          | 2                 | 35.55      | 29.71, 35.39  | 94% 126.4(1) P < 0.001 |
| Year of publication   |                   |             |                |  |
| 2016 and after (1, 4, 6, 7, 9, 10) | 6 | 35.47 | 32.85, 38.09 | 94.5% 159.5(5) P < 0.001 |
| Before 2016 (2, 3, 5, 8) | 4 | 56.26 | 32.51, 80.04 | 96.2% 289.1(3) P < 0.001 |
| Measurement tool      |                   |             |                |  |
| Kilifi stigma scale (3, 4, 9, 10) | 4 | 33.63 | 31.98, 35.67 | 94.6% 158.32(3) P < 0.001 |
| Three item stigma scale (6, 8) | 2 | 39.5 | 35.97, 43.03 | 96.8% 295.17(1) P < 0.001 |
| Modified FIS (2, 5)   | 2                 | 76.3       | 67.8, 85.67   | 98% 362.20(1) P < 0.001 |
| Others (1, 7)         | 2                 | 35.9       | 26.49, 45.31  | 94% 125.2(1) P < 0.001 |

Key: Others imply Jacoby stigma scale and non-specified tool, FIS: Family Interview Schedule, SNNP: Southern Nations Nationalities and Peoples

Sensitivity analysis

We also wander for the source attributable to the difference between studies variance by employing one study leave out at a time sensitivity analysis. The result obtained showed that the average prevalence of perceived stigma ranges between 39.66% and 45.20% when every 10 studies were excluded at a time.

This was in between the 95% confidence interval of pooled prevalence of perceived stigma when all 10 studies were pooled together. Therefore, our meta-analysis result was not out-weighed by a single influential study (Table 4).
Table 4
A sensitivity analysis of the Prevalence of Perceived Stigma among Epilepsy Patients in Ethiopia when each indicated studies were removed at a time with its 95% confidence interval.

| No | Study excluded | Prevalence of perceived stigma (%) | 95% Confidence interval | Remark |
|----|----------------|-----------------------------------|-------------------------|--------|
| 1  | Tegegne,2016 (1) | 44.13 | 30.71, 57.76 |        |
| 2  | BB Biftu et al 2015 (2) | 40.7 | 27.81,52.59 |        |
| 3  | Fanta et al.2015 (3) | 45.19 | 32.35, 58.02 |        |
| 4  | Tiki et al.2018 (4) | 44.8 | 31.82,57.45 |        |
| 5  | Shibire et al.2009 (5) | 39.66 | 31.43, 47.88 |        |
| 6  | Chaka et al.2018 (6) | 44.47 | 31.16, 57.77 |        |
| 7  | Angelo et al.2018 (7) | 45.20 | 32.42, 57.98 |        |
| 8  | Tsegabirha et al.2014 (8) | 44.07 | 30.84, 57.62 |        |
| 9  | Getinet et al.2016 (9) | 44.78 | 31.62, 57.92 |        |
| 10 | M Shegaw .2017 (10) | 44.88 | 31.96, 57.80 |        |

Figure 1: PRISMA flow chart for the review search process
Figure 2: A forest plot for the prevalence of perceived stigma among epilepsy patients in Ethiopia
Figure 3: A forest plot for the sub-group analysis of the prevalence of perceived stigma among epilepsy patients in Ethiopia
Figure 4: A funnel plot for the prevalence of perceived stigma among people living with epilepsy in Ethiopia

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regarding chronic illness in general and epilepsy, in particular that could probably reduce the average perceived stigma than the population in the
region (28).

Furthermore, the average prevalence of perceived epilepsy stigma was significantly higher in studies from the Amhara region (29). A sub-group analysis of perceived stigma with measurement tool used to screen perceived stigma revealed that the average prevalence of perceived stigma in people living with epilepsy was substantial (43.79%). This was lower than the prevalence of perceived epilepsy stigma reported by a study that assessed more than 5,000 people living with epilepsy in 15 European countries where the reported prevalence of perceived stigma was 51% (14). The result of the present study was also lower than a study on systematic review and meta-analysis on the prevalence, associated factors, and impacts of personal stigma in patients with schizophrenia spectrum disorders whereby 64.5% of patients had perceived stigma (45). The long time difference between the present and earlier studies might be responsible for this. Besides, the loss of judgment and insight in most people with schizophrenia spectrum disorders might affect the higher prevalence of perceived stigma.

The average prevalence of perceived stigma in this study was however higher than the prevalence of perceived stigma in ten European countries where the overall prevalence of perceived stigma was 17% (14). Differences in cultural, economic, and associated attitudinal factors where the European countries are economically advanced and health care utilization in this setting might be high and reduces the perception of stigma.

The average prevalence of perceived stigma in people living with epilepsy varies according to the measurement tool used to assess perceived stigma, the location of study, and year of publication.

A sub-group analysis of perceived stigma with measurement tool used to screen perceived stigma revealed that the average prevalence of perceived stigma in studies measured with modified FIS scale (20, 27) was significantly higher than the average prevalence of perceived stigma in studies measured with Kilifi stigma scale and three-item stigma scale.

The modified FIS scale is a WHO-approved tool for screening perceived stigma. Also, its Amharic version is validated in Ethiopia so that that it can sensitively detect epilepsy patients with perceived stigma but in most of the included studies that utilized Kilifi stigma scale (29–31, 33), the 66th percentile is used as the cut-off point that might not be as such sensitive to detect perceived stigma. Moreover, the small number of studies included in the sub-group of the FIS scale might result in an overestimation of the result and gives a higher prevalence of perceived stigma than studies assessed with the Kilifi stigma scale.

Furthermore, the average prevalence of perceived epilepsy stigma was significantly higher in studies from the Amhara region (27, 30) and Oromia region (20, 33, 34) than the pooled prevalence of perceived epilepsy stigma in Addis Ababa (28, 29, 32). The population living in Addis Ababa, the capital city of Ethiopia is relatively developed in terms of knowledge, social, and cultural views. Therefore they might have a better attitude regarding chronic illness in general and epilepsy, in particular that could probably reduce the average perceived stigma than the population in the

| No | Study | Prevalence of perceived stigma (%) | 95% Confidence interval | Remark |
|----|-------|-----------------------------------|-------------------------|-------|
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### Discussion

To date, the researchers of the current study assured that this review and meta-analysis on the average prevalence of perceived stigma and its associated factors in people living with epilepsy is the first of its kind in the context of Ethiopia. Therefore, the result obtained from this meta-analysis on the prevalence of perceived stigma in people living with epilepsy will be significant evidence to clinicians, future researchers, and any other interested bodies planning to design interventional as well as administrative policy in the field.

The average prevalence of perceived stigma in people living with epilepsy in Ethiopia was substantial (43.79%). This was lower than the prevalence of perceived stigma reported by a study that assessed more than 5,000 people living with epilepsy in 15 European countries where the reported prevalence of perceived stigma was 51% (14). The result of the present study was also lower than a study on systematic review and meta-analysis on the prevalence, associated factors, and impacts of personal stigma in patients with schizophrenia spectrum disorders whereby 64.5% of patients had perceived stigma (45). The long time difference between the present and earlier studies might be responsible for this. Besides, the loss of judgment and insight in most people with schizophrenia spectrum disorders might affect the higher prevalence of perceived stigma.

The average prevalence of perceived stigma in this study was however higher than the prevalence of perceived stigma in ten European countries where the overall prevalence of perceived stigma was 17% (14). Differences in cultural, economic, and associated attitudinal factors where the European countries are economically advanced and health care utilization in this setting might be high and reduces the perception of stigma.

The average prevalence of perceived stigma in people living with epilepsy varies according to the measurement tool used to assess' perceived stigma, the location of study, and year of publication.

A sub-group analysis of perceived stigma with measurement tool used to screen perceived stigma revealed that the average prevalence of perceived stigma in studies measured with modified FIS scale (20, 27) was significantly higher than the average prevalence of perceived stigma in studies measured with Kilifi stigma scale and three-item stigma scale.

The modified FIS scale is a WHO-approved tool for screening perceived stigma. Also, its Amharic version is validated in Ethiopia so that that it can sensitively detect epilepsy patients with perceived stigma but in most of the included studies that utilized Kilifi stigma scale (29–31, 33), the 66th percentile is used as the cut-off point that might not be as such sensitive to detect perceived stigma. Moreover, the small number of studies included in the sub-group of the FIS scale might result in an overestimation of the result and gives a higher prevalence of perceived stigma than studies assessed with the Kilifi stigma scale.

Furthermore, the average prevalence of perceived epilepsy stigma was significantly higher in studies from the Amhara region (27, 30) and Oromia region (20, 33, 34) than the pooled prevalence of perceived epilepsy stigma in Addis Ababa (28, 29, 32). The population living in Addis Ababa, the capital city of Ethiopia is relatively developed in terms of knowledge, social, and cultural views. Therefore they might have a better attitude regarding chronic illness in general and epilepsy, in particular that could probably reduce the average perceived stigma than the population in the
Amhara and Oromia region. Further to this, both Amhara and Oromia regions are the two most populated regions in Ethiopia so that the health care coverage of these populous regions is still low which might contribute to the high average perceived stigma in the regions.

We also did a segmental analysis of the prevalence of perceived stigma on the ground of year of publication of the included studies and studies published before 2016 (20, 27, 29, 34) provide higher average perceived stigma (56.26%) than studies published in and after 2016 (26, 28, 30–33) (35.47%). This might be because increased awareness of people towards epilepsy is expected as the country's economic development is advancing through time that lowers the perceived stigma. Further to this the relatively few studies included in the sub-group of studies published before 2016 as compared to the sub-group of studies published in and after 2016 could minimize the precision and result in an overestimation of perceived stigma.

Relating to the factors associated with perceived stigma in people living with epilepsy, a narrative analysis revealed that being divorced/widowed, living in rural areas, low level of education, low-income level, age groups of 18 to 24 years, frequent seizure occurrence, contagion believe regarding epilepsy, seizure-related injury, duration of epilepsy from 1 to 10 years, depression and anxiety co-morbidity were the associated factors with perceived stigma in people with epilepsy in Ethiopia.

This was supported by earlier review studies abroad, whereby rural residence, lower-income, and educational status, being female, and single, not witnessing individuals having the disorder, contagious believe regarding epilepsy and mental illness co-morbidity were reported to be associated with perceived stigma in epilepsy (35, 36). However, a review of literature in Nigeria had shown that people with epilepsy are felt stigmatized due to the psychopathology associated with epilepsy (37).

The difference between studies included in the meta-analysis

This review and meta-analysis study was prejudiced by a great heterogeneity from the difference between analyzed studies. Therefore consideration of sub-group and sensitivity analysis was instigated. The analysis of the sub-group was done under the assessment instrument for perceived stigma, regional setting, and year of publication of studies. All the above three dimensions of subgroup provide subtle evidence from where was the difference between studies arise. Even though a sensitivity analysis was done, there was no implication of a single study outweighing the average prevalence of perceived stigma in people with epilepsy in Ethiopia.

In using the results of the present meta-analysis study, we should take into consideration its shortcomings. Primarily, a few numbers of studies have been pooled in the subgroup analysis based on measurement tool, study location, and publication years with the possibility of influence on estimate precision. Further to this, the occurrence of great heterogeneity in the pooled prevalence of perceived stigma was also a constraint to the plausibility of the study. Finally, a sole narrative analysis of the associated factors for perceived stigma in individuals living with epilepsy still requires further exploration of the average effect size of associated factors by future researchers. The shortage of earlier meta-analysis studies in people living with epilepsy has also made the comparison the results of the present study difficult and should be taken into consideration.

Conclusion

The pooled prevalence of perceived stigma in people living with epilepsy in Ethiopia was substantial (43.79%) and was under the effect of the high difference between studies analyzed. A sub-group analysis discovered that the average prevalence of perceived stigma was significantly higher in studies measured with a modified FIS scale than the average prevalence of perceived stigma in studies measured with the Kilifi stigma scale and three-item stigma scales. In addition to this, the average prevalence of perceived epilepsy stigma was much higher in studies from Amhara and Oromia region than the prevalence of perceived epilepsy stigma in Addis Ababa and SNNP.

Moreover, studies published earlier to 2016 provide higher pooled perceived stigma than studies published in and after 2016. Even though a sensitivity analysis was done, none of the included studies was outweighing the overall study result. Qualitative analysis revealed that being divorced/widowed, living in rural areas, low level of education, low-income level, age groups of 18 to 24 years, frequent seizure occurrence, contagion believe regarding epilepsy and seizure-related injury, duration of epilepsy from 1 to 10 years, depression and anxiety co-morbidity were among the associated factors with perceived stigma in people with epilepsy in Ethiopia. This pooled evidences regarding perceived stigma in people living with epilepsy in Ethiopia plays a significant role as it disclosed substantial evidence for future interventional accomplishments in the field. Great emphasis should, therefore, be given to the aforementioned findings in the management procedures for people with epilepsy.

Abbreviations

CI: Confidence Interval, CS: Cross-sectional, FIS: Family Interview Schedule, LMICs: Low and Middle-Income Countries, OR: Odds Ratio, PRISMA-P: Preferred Reporting Items for Systematic Reviews and Meta-analysis, SNNP: Southern Nations Nationalities and Peoples, WHO: World Health Organization.
Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not Applicable

Availability of data and materials
All of the working data for this meta-analysis study is in the manuscript.

Competing interests
We authors have no competing interests for this study.

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Authors' contributions
MN conceived the idea to conduct a review and meta-analysis study on perceived stigma. This author developed the protocol and delineated the search strategies with the appropriate search databases. MN did the qualitative as well as meta-analysis and writes the manuscript. MN and MB extracted the important data from the included studies. MN and SG assessed the quality of included studies. All authors reviewed and approved the final draft of the manuscript.

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**Figures**

**Figure 1**

PRISMA flow chart for the review search process

**Figure 2**

A forest plot for the prevalence of perceived stigma among epilepsy patients in Ethiopia
Figure 3

A forest plot for the sub-group analysis of the prevalence of perceived stigma among epilepsy patients in Ethiopia.

| Tools | ES (95% CI)     | % Weight |
|-------|------------------|----------|
| Modified FIS | 71.66 (61.30, 81.92) | 10.00 |
| Osnis et al 2015 | 61.68 (39.63, 81.17) | 10.00 |
| Subtotal (I^2 = 93%, p < 0.001) | 76.50 (67.08, 85.51) | 30.00 |
| KABHI stigma scale | 31.26 (29.87, 32.65) | 10.00 |
| Tuck et al 2015 | 34.69 (34.17, 35.18) | 10.00 |
| Gachet et al 2016 | 34.96 (34.69, 35.08) | 10.00 |
| M Shagaf 2017 | 34.96 (33.79, 35.98) | 10.00 |
| Subtotal (I^2 = 94.6%, p < 0.001) | 35.96 (31.98, 39.94) | 80.00 |
| Others | 42.79 (40.59, 45.0) | 10.00 |
| Tewa 2016 | 35.96 (36.54, 45.51) | 20.00 |
| Subtotal (I^2 = 94%, p < 0.001) | 35.96 (31.98, 39.94) | 100.00 |
| Three item stigma scale | 37.76 (37.59, 37.93) | 10.00 |
| Chikala 2018 | 37.76 (37.59, 37.93) | 10.00 |
| Subtotal (I^2 = 78.8%, p < 0.001) | 38.59 (38.07, 42.22) | 20.00 |
| Overall (I^2 = 77.6%, p < 0.001) | 38.59 (33.84, 53.27) | 100.00 |

NOTE. Weight are from random effects analysis.

Figure 4

A funnel plot for the prevalence of perceived stigma among people living with epilepsy in Ethiopia.

Supplementary Files

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