

Review

Does public attitude change by labeling a person as epileptic, person with epilepsy or the acronym PWE? A systematic review

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ABSTRACT

Purpose: It is still unknown if attitudinal differences by diverse labeling of persons with epilepsy could be universally accepted with the actual literature evidence. The manner in which questions are constructed could also have an impact in final results. The purpose of this systematic review was to examine the published articles regarding changes in public's attitude towards epilepsy by labeling a person as epileptic, person with epilepsy or with the acronym PWE.

Methods: We undertook a systematic review of the literature using common databases with specific keywords and combinations searching for original articles, meta-analysis and systematic reviews. Sociodemographic variables, attitude results and questions style were analyzed in included articles.

Results: Four original articles were found. Significant attitudinal changes were described in three studies with the label person with epilepsy. One study failed to demonstrate an attitudinal change by distinct labeling of a person with epilepsy. All questions were formulated in a personal way. Few neutral and mostly induced questions were found in the studies.

Conclusion: By the use of the label "person with epilepsy" there is a trend towards positive changes in public's attitudes, although evidence is scarce to consider this tendency as universally applicable. More studies are needed considering widespread social and cultural backgrounds and patient opinion. Language power by wording type could be a key consideration for future studies.

1. Introduction

Epilepsy is considered a public health priority and carries since ancestral times a high burden of stigmatization [1–3]. Negative perceptions towards the condition could limit patient's social interaction, schooling, work and may affect their quality of life, leading them to hide their diagnosis in order to protect themselves from the effects of stigma [4,5]. Disease definition and classification based on etiologic, pathophysiologic, diagnostic, therapeutic and prognostic knowledge are helpful in clinical practice, but descriptions usually do not consider personal characteristics like cultural, psychologic, spiritual or social backgrounds [6]. It is possible to displace the integrity and dignity of human beings by superimposing the condition as a result of labeling an affected person with the diagnostic nomenclature [7]. Language gives necessary information for building concepts that could modulate

perceptions and thoughts according to individual or group intentions [8]. Today the terms *epileptic* and *person with epilepsy* (PWE) are frequently used interchangeably in verbal and written communication. Even more the concept of person with epilepsy is frequently shortened in English and Spanish literature and talks to the acronym PWE (PCE for "persona con epilepsia" in Spanish), which also aroused discussions between patients and clinicians [9–11]. Nevertheless it is still unknown if these attitudinal differences by diverse labeling could be universally accepted with the actual literature evidence.

The way questions are constructed could have an impact in the answers. In that sense personal directed questions will reflect more the individual's attitude than the general social expected position. As an example it is plausible to get different answers to the following questions: Would you marry a person with epilepsy? and Should persons with epilepsy marry? The other point in questioning is the possibility of

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answer induction through positive or negative wording instead of using neutral sentences. Again it is plausible to get different answers to the following questions: Would you marry a person with epilepsy? and Would you marry a patient with epilepsy? In the first question the concept of person is put in the first level and the condition in the second level. The other question has modified the word of person to patient which is now the highlighted noun. In question construction the aim could change if the idea is presented in a noun, adjective or as a possessive form.

The purpose of this systematic review is to examine the published articles regarding changes of public's attitude towards epilepsy by labeling a person as epileptic, person with epilepsy or with the acronym PWE and to review the type of questions offered to the interviewed populations.

2. Methods

2.1. Search

The search strategy for this systematic review was applied in databases like Embase®, Index Medicus®, Medline®, Google Scholars, Current Contents, Scielo and Cochrane, to find articles published from January 1990 to November 2018. The search included subject headings for literature on attitude and epilepsy. The following keywords were used: attitude, awareness, discrimination, epilepsy, epileptics, epileptic, exclusion, person with epilepsy, epileptic social stigma, labeling, language, language expression, people with epilepsy, perception, PWE, prejudice, seizures, social stigma, social perception, rejection, stereotype, stigma, terminology, quality of life. We screened reviews, meta-analysis, editorials, letters to editors, case series, original articles and book chapters. Article bibliographies were screened to identify additional papers.

2.2. Study selection

Titles and abstracts were reviewed to select original articles regarding effects on attitude by labeling a person with the terms epileptic, person with epilepsy or PWE. Inclusion criteria were articles that analyzed questions with the above mentioned terms and their impact in stigma related attitude. Articles written in a language other than English, French, Spanish or Portuguese, were excluded. (Fig. 1).

2.3. Data collection process

After consensus all authors reviewed the articles independently to extract information about: questionnaires, sociodemographic characteristics including country, age, gender, epilepsy knowledge and target population. After group agreement three types of questions about the attitude by labeling a person were defined as general, neutral or induced questions.

3. Results

A total of 18,156 articles meeting the search keywords were identified. After filtering through observational study, clinical study, systematic review, meta-analysis and review 190 articles were found (Fig. 1). Only four studies met the inclusion criteria [12–15].

The four articles focused on the following populations: school or gymnasium students, psychology and medical students, adults with epilepsy and relatives and friends of PWE. These studies were done in Brazil, Croatia and two in the United Kingdom (UK). Female gender represented a 75,5% and adults 65,3% of all interviewed people. Domains evaluated in Brazilian and Croatian studies included employment, schooling and marriage opportunities as well as risk for segregation of people with epilepsy. Three studies used questions differentiating the labels of “epileptic” versus “PWE”. The 2017 UK study

presented three different types of PWE denomination phrases (traditional label, disability-first and person-first). This study identifies preference of patients and significant others for person-first label [15].

The studies tried to avoid selection bias by randomly assigning the questions to the people surveyed [12–14].

A significant favorable attitude change, different from the term preference of 2017 UK study, was demonstrated with the label “person with epilepsy” in the others two studies Brazil [$p < 0.001$], Croatia [$p < 0.05$], and 2016 UK the word “epileptic” did not provoke more negative attitudes [12–14]. The Brazilian study did not demonstrate changes in the attitude of the respondents regarding variables of sex, religion or prior knowledge of the disease [12]. In contrast the Croatian study showed that women, self-perceived as religious and having knowledge of epilepsy had negative attitudes when using the term “epileptic” [13]. The 2016 UK study reported that non-White British ethnicity had higher perception of PWE being rejected by society [14]. The 2017 UK study found that in increased age and being parent to someone with epilepsy disliked the traditional term “they are epileptic” [15].

No study mentioned the acronym PWE as a possible option in attitude change.

Concerning construction of questions all four studies had only personal formulated questions. Negative induction was found in fifteen questions distributed in three articles. The authors considered question induction when nouns, adjectives or adverbs had a positive or negative meaning or connotation. (Tables 1 and 3)

4. Discussion

Epilepsy remains a highly stigmatizing condition worldwide and language may modulate public attitude towards PWE. The use of person-first term “person with epilepsy” demonstrated a significant favorable attitude in two articles, and was the preferred label in a third study. Another study did not reflect a negative attitude with different labels (Table 2).

Based only on four published studies there is a trend but not enough evidence to launch a global acceptable destigmatizing recommendation for labeling a PWE.

All four studies took place in three countries, leaving behind other communities with different social and cultural backgrounds. Public concept of epilepsy varies across cultures, and language may reinforce positive or negative social imaginary. It is the case of Korea where the traditional name for epilepsy *gan-jil*, “crazy convulsive disease”, was changed in 2010 to a neutral name *noi-jeon-jeung* that means cerebroelectrical disorder. This change was made taking into account that stigma towards people with epilepsy impacts their quality of life in a more significant way than the disease itself. Other Asian, African and Latin American communities have also a negative connotation in their common language for epilepsy. [16]

The female overrepresentation in all four studies could be a selection bias or a sign that labeling is a major concern for women but not that much for men. Gender distribution in epilepsy epidemiological studies is usually equal. Heterogeneous sample distribution might change final results significantly. Some authors have pointed out that for several reasons literature on epilepsy has a selected focus on female issues. A nationwide survey on epilepsy in the UK demonstrated that men with epilepsy felt comfortable discussing their epilepsy, confident in asking for information and that the condition adversely affected their self-esteem and quality of life [17,18].

From all interviewed population, 65.3% were adults, persons under fifteen were not included (Table 1). Asking children and teenagers with epilepsy about their preferred naming and perceived attitude is important. Besides epilepsy, academic failure or underachievement, cognitive and behavioral comorbidity are frequent in these populations and may contribute further to stigma [19,20]. It is possible that acceptable social labeling contributes to more opportunities in terms of social

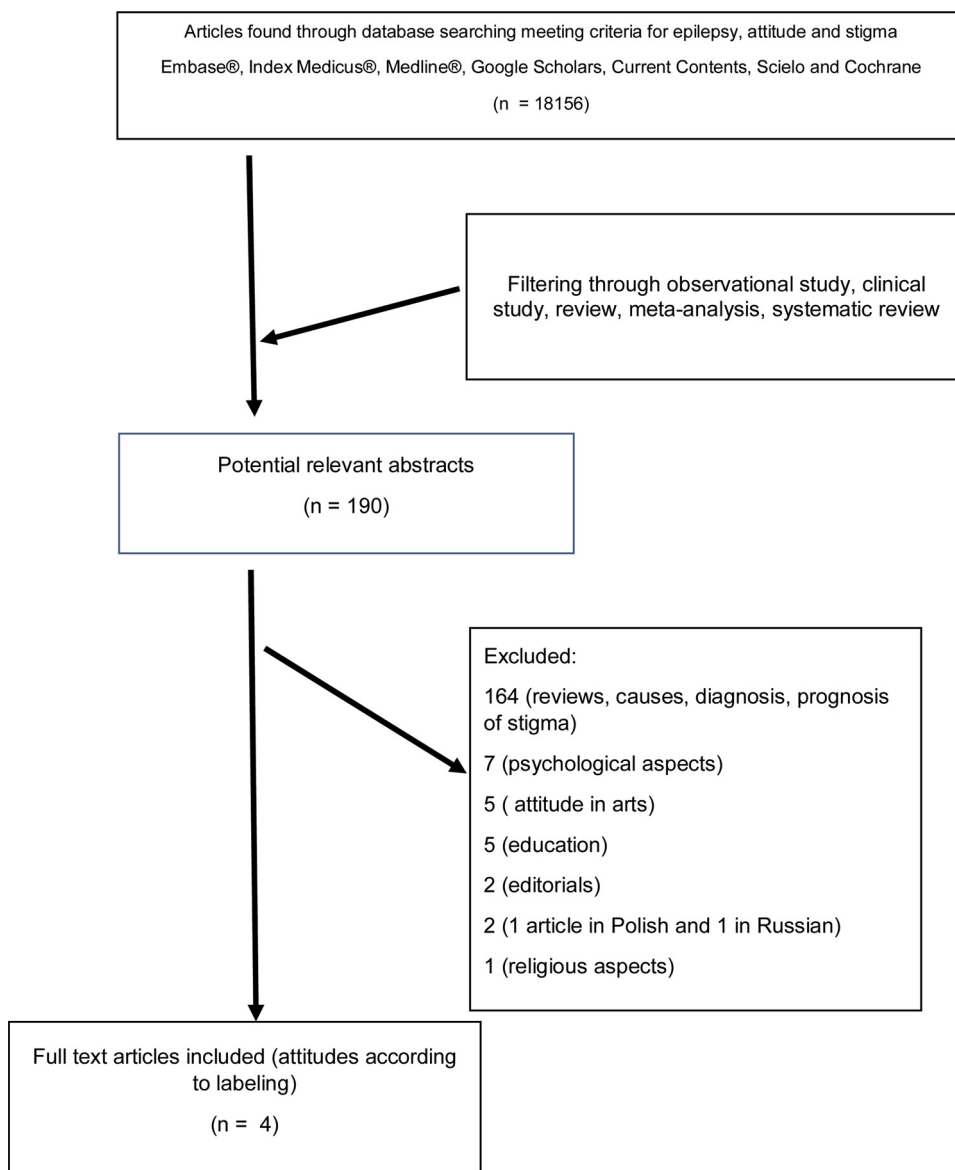


Fig. 1. Flowchart of the literature search.

inclusion, sensitization towards public policies in epilepsy, defense of human rights and improvement of quality of life.

The samples included only school and undergraduate students, PWE and epilepsy patients significant others. Other important social stakeholders should be interviewed in studies about labeling and consequent attitude towards PWE. Employers preferred the label epilepsy in a cover letter than the terms seizure disorder or seizure condition, but recommended that applicants should not disclose their disability in a cover letter. The literature review of Smeets et al. focused on how stigma, seizure severity, and psychosocial variables such as low self-esteem, passive coping style, and low self-efficacy have been implicated as factors that play an important role in predicting employment. Wo et al. demonstrated similar results eight years later [21–23]. The prejudice towards students with epilepsy persisted in Italian school teachers even after receiving epilepsy courses; on the other side the knowledge gap diminished after the courses. Teachers of Saudi Arabia considered epilepsy a psychological disorder (56%), would not approve a son/daughter marriage to a PWE (68%) and believed that a PWE could not be successful in high-ranking professions (46%) [24,25].

Questions presented to interviewed people need also special considerations. Authors found fifteen negatively induced questions, three

neutral ones and no positive induction. Labeling and attitude measuring questions should be as neutral as possible without a sign of positive or negative answer induction. They should avoid researchers’ or common social positions and should be presented as personal instead of generic questions to accomplish personal attitude instead of social accepted norms. It is possible that the difference between *epileptic* compared with *person with epilepsy* will have at the end similar results in otherwise equal sentences, but it is also possible that the magnitude of the stigmatization effect could be higher in both situations due to negative statements. It is conceivable that negative questions or statements could induce negative answers; examples of negative induced questions and neutral alternatives are shown in Table 3. The substitution of the label “person with epilepsy” for “epileptic patients” or “epileptics” in a general attitude questionnaire could have a different impact in attitude. The nouns person, patient and epileptic do not have the same meaning, are not interchangeable and could have different power in attitude questionnaires [26].

All questions were formulated in a personal and not in a general form. The study of Singh et al. showed that stigma is elicited to a greater degree by using personal instead of generic questions considering marriage in epilepsy. The authors do not mention the impact of

Table 1
Age, gender distribution and type of questions applied to the of studied population.

| Country / year | Groups | Sample | % | Age range (years) | Sex (n / %) | | Type of questions (n) | | | |
|--------------------------|---|--------|------|---------------------------|-------------|-------------|-----------------------|-------------------|-------------------|-------------------|
| | | | | | Male | Female | Personal questions | General questions | Neutral questions | Induced questions |
| United Kingdom/2017 (15) | Patients with epilepsy Relatives and friends of PWE School students | 638 | 34.6 | 20 to 81 | 149 (23.4) | 489 (76.6) | 1 | 0 | 1 | 0 |
| | | 333 | 18 | 20 to 81 | 35 (10.5) | 298 (89.5) | | | | |
| | | 425 | 23.4 | 15 to 19 | 164 (39) | 256 (61) | 9 | 0 | 2 | 7 |
| Brazil / 2009(12) | Students of psychology or medicine | 214 | 11.3 | No age range ^a | 62 (29) | 152 (71) | 4 | 0 | 0 | 4 |
| United Kingdom/2016 (14) | | 234 | 12.7 | 18 to 42 | 42(18) | 192 (82) | 4 | 0 | 0 | 4 |
| Total | | 1844 | 100 | | 452 (24.5) | 1387 (75.5) | 18 | 0 | 3 | 15 |

^a average age 16 years.

Table 2
Studies on public attitude according to the labeling a person with epilepsy.

| Country/Year | Study design | Case N/Controls N | Results | Observations |
|-----------------------------------|---|---------------------------------------|--|---|
| Brazil / 2009 ² | Cross sectional Comparison of group 1 (questionnaire “person with epilepsy”) with group 2 (questionnaire “epileptic / epileptic child”). Gifted students in summer camp. | 105 / 109 | Group-1 responded that 62% of PWE and group-2, that 93% of epileptics have more difficulty finding employment (p < 0.001). Group-1 responded that 37% of PWE and group-2, that 70% of epileptics have more difficulties at school (p < 0.001). Group-1 responded that 41% of PWE and group-2, that 87% of epileptics are rejected by the society (p < 0.001). Stigma score was higher in group 2. More negative attitudes in group B (p = 0.008), also when asked about sharing a room with a person with epilepsy (p = 0.005) and marrying a person with epilepsy, either themselves (p = 0.033) or when the person getting married is someone close to them (p = 0.024). A comparison of their responses to the attitude measures revealed no statistically significant or meaningful differences between different labeling. | Personally directed questions. Some questions including both labels that could have negative connotations like “...have more difficulties...” or “...are rejected by...” |
| Croatia / 2015 ³ | Cross sectional Comparison of group A (questionnaire “person with epilepsy”) with group B (questionnaire “epileptic / epileptic child”). Gymnasium students, 15 to 19 year old were used. | 208 / 217 | More negative attitudes were disclosed by those who declared themselves as religious. Those with knowledge about epilepsy and affected relatives had better attitudes. Some questions with negative connotations. | More negative attitudes were disclosed by those who declared themselves as religious. Those with knowledge about epilepsy and affected relatives had better attitudes. Some questions with negative connotations. |
| United Kingdom/ 2016 ⁴ | Cross sectional online survey in psychology and medical school. For Group 1: terms “person with epilepsy” or “people with epilepsy”. Group 2: terms “epileptic” and “epileptics” were used. | 118 / 116 | Personally directed questions. Some questions with negative connotations. | Personally directed questions. Some questions with negative connotations. |
| United Kingdom/ 2017 ⁵ | Cross sectional online survey with patients and significant others (family, friends). Three distinct phrases were presented: “They’re epileptic” (traditional label), “They’re an epileptic person” (disability-first) and “That person has epilepsy” (person-first). | 638 patients / 333 significant others | The majority of those with epilepsy (86.7%, 95% CI 84.0–89.3) and significant others (93.4%; CI 90.7–96.0) chose the person-first term. Traditional and disability-first terms were disliked or strongly disliked. | Person first terminology affirms personhood before disability; it lessens negative associations and suggests some mastery over their condition. |

Table 3
Types of questions according to induction or neutrality meanings.

| Study | Question with possible induction | Induction words | Neutral alternatives |
|---|--|--|--|
| Brazil ¹² and UK ¹⁴ | Do you think that people with epilepsy/epileptics are rejected by the society? Do you think that people with epilepsy/epileptics have more difficulties at school? Do you have prejudice toward people with epilepsy/epileptics? | rejected more difficulties prejudice | Do you think that people with epilepsy/epileptics have same opportunities in society? Do you think that people with epilepsy/epileptics have same chances or achievements at school? Do you have the same opinion, feeling or thoughts toward people with epilepsy compared with people without epilepsy? |
| Croatia ¹³ | Do you think that people with epilepsy/epileptics have more difficulties to get employed? I would object my brothers/sisters playing with children who have epilepsy I would object if one of my closest friends/family members married a person with epilepsy I would mind working with a person with epilepsy It would be a problem for me to marry a person with epilepsy I would mind sharing a room with a person with epilepsy I would feel unpleasant in a longer conversation with a person with epilepsy I would feel ashamed if people knew I had a person with epilepsy in my family | more difficulties object object mind be a problem mind unpleasant ashamed | Do you think that people with epilepsy/epileptics have the same opportunities to get employed? I would let my brothers/sisters playing with children who have epilepsy I would feel the same if one of my closest friends/family members married a person with epilepsy I would work with a person with epilepsy I would marry a person with epilepsy I would share a room with a person with epilepsy I would feel equal in a longer conversation with a person with epilepsy I would feel the same if people knew I had a person with epilepsy in my family |
| Neutral Questions | | | |
| Study | Question | | |
| Croatia ¹³ | I think that a person with epilepsy could perform most of the jobs that people who do not have epilepsy could I could be a friend with a person with epilepsy | | |
| UK ¹⁵ | What do you think about some words and expressions which people sometimes use? They're epileptic, They're an epileptic person, That person has epilepsy | | |

positive, neutral or negative statements on stigma after classifying the questions [27]. In this review three studies used personal and negative statements. To our knowledge there are no studies evaluating attitude towards epilepsy according to positive, neutral or negative placed questions or regarding to personal or generic formulations.

Wording could also be an important issue to analyze at labeling PWE. In English, like in other languages as Spanish, PWE are referred in three possible linguistic forms: a. As nouns, “he is an epileptic” or “person with epilepsy” b. As adjectives, “epileptic person” c. As possessive forms, “she has epilepsy”. Nouns assign a person, animal or object to a category. Categories have the characteristics of central identity formation, are relatively permanent, permit more inferences, provide more essential information and usually do not overlap with other categories. Nouns stay for the essentialism of the entity and not for the qualities of the entity. Nouns have a more powerful impact on person perception than adjectives. Linguistic characteristics of adjectives support fewer inferences, are less enduring, are not central to identity, permit distinctions of degree (more or most beautiful), are subordinated to nouns and give different semantically meanings (male athlete vs athletic man) and describe only a single property of a person, object or animal. Possessive forms are not necessarily attributes, have variable duration and are also noun subordinated [28,29]. The label person with epilepsy is political correct, academically accepted and preferred by patients and significant others in the UK study. It gives the preponderance to the human being and its inherent dignity. Person first terminology affirms personhood before disability; it lessens negative associations and suggests some mastery over their condition [15,30,31].

Other authors have a different opinion towards the label of person first and the condition at a second level. Arguments are that the label person first is artificial, not common use, hides the condition (disability, disease), does not have necessarily an impact in attitude and has a restricted boring connotation in written and spoken language. The acronym PWE is used for space economy and might lose its initial intention that does not pass unperceived by the general community or patients [10]. Artificial or unusual labels like “person with epilepsy” does not rely in popular use but are used when negative attributes are relevant. Usually you do not say “woman with beauty or student with intelligence” instead of “beautiful woman or intelligent student”. In this sense and given the power in identity of nouns it is plausible to think that the label person with epilepsy could carry a negative “unconscious” connotation because of its artificial construction [32]. The English study with epilepsy and another one of Florida focusing on disabilities did not demonstrate attitude differences according to diverse labeling [13,33]. It might be that the label “person with ...” carries also a negative connotation without inducing a better attitude despite its political correctness and social acceptance. Another possible explanation is that patients and relatives do not really mind with nouns putting the condition in the label’s front like autistic or epileptic. Patients may develop coping strategies independently from labeling. The study by Kenny et al. showed preference for the naming “autistic” in the case of patients and relatives and the preference of the term “person with autism” by professionals [34,35]. Psychiatric patients can also vary their label preference according to the professional who will make contact with them. They do not necessarily mind if they are named as patients when communicating with direct health care providers, or clients when they are in front of administrative staff or social workers in a clinical setting [36]. The social burden and stigma of mental illness are higher than that of physical illness. Mental illness has also a higher enduring effect in public imaginary, even being invisible compared with physical disease. It might be that epilepsy is included in the mental illness category for the general community. In that case it is possible that whatever the label is the attitudes will not necessary change [29,37].

5. Conclusion

There is a trend to positive changes in public's attitudes towards the condition by the use of the label "person with epilepsy" although the evidence is scarce to consider this trend as universally applicable, taking into account gender, age, ethnicity, knowledge, language and cultural differences. Only one study evidenced the patients labeling preference for the term "person with epilepsy" so it remains unexplored in most regions of the world. In the same sense more stigma studies are needed to explore attitude changes towards PWE when questioned using different labels and wording. Language power by wording type in research questionnaires may have an important impact in final attitude.

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Conflict of interests

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