

REVIEW ARTICLE

Attitudes toward epilepsy, a systematic review

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Abstract

Surveys about attitudes towards those with epilepsy have been performed since 1949, in order to understand the social stigma toward epilepsy. This review aims to demonstrate the variation in public attitudes towards epilepsy and its associated factors, with a critical review of the methodology used to examine attitudes towards epilepsy. There was marked variation of attitudes between Western and non-Western populations, and these attitudes were positively correlated with the standard of living. Besides the general public, studies were also performed within specific groups, particularly teachers and students. However absence of a standardized questionnaire makes direct comparison difficult. A few quantitative methods were developed but these were limited by cultural variations and thus lack of global acceptance. Short-term intervention studies demonstrate an improvement of attitude with knowledge. Nonetheless, the cultural and social reasons underlying the attitudes, and how this affects the life of people with epilepsy, are understudied. Therefore, surveys on attitudes should continue to be carried out, particularly in populations prone to have negative attitudes with emphasis on underlying reasons, and such progress should be monitored longitudinally. Attitudes of people such as parents, teachers, school counselors, health care professionals, and employers, which have a direct impact on people with epilepsy, should be more extensively studied.

INTRODUCTION

Epilepsy is a disorder of the brain that is characterized by an enduring predisposition to generate seizures and by its neurobiological, cognitive, psychological, and social consequences.¹ A meta-analysis showed that the median lifetime epilepsy prevalence for developed countries was 5.8 per 1,000, as compared to 15.4 per 1,000 for rural and 10.3 for urban studies in developing countries.²

However, epilepsy is often an underappreciated health problem especially in Asia.³ In developing countries, 60% to 90% of people with epilepsy receive no treatment due to inadequacies in health care resources and delivery, and due to social stigma.^{4,5}

People with epilepsy are burdened by a multitude of social, psychological and economic consequences of stigmatization which leads to poor quality of life.^{6,7} Stigma is precisely described by Boer as follows: children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe.⁷ This explains how people with epilepsy are marginalized in the society

as a result of negative public attitudes towards epilepsy.

The earliest research in social stigma was to examine public attitudes towards epilepsy by Caveness in the United States in 1949.⁸ This was a population-based study, which was subsequently repeated at 5-year intervals, until 1979.⁹⁻¹⁴ Since then, similar studies were repeated in various countries and regions, in selected populations (e.g., teachers, health care providers), and in various languages.

In this review, we aim to determine the variability of public attitudes towards epilepsy among different populations, across time, and between different study populations as well as the challenges in comparing results obtained from studies using differing methodology. The pros and cons of various study methods will then be analyzed and discussed, aiming to guide future research in attitudes towards epilepsy.

METHODS

Search strategy and selection

MEDLINE and EMBASE database were systematically searched by the first and second

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author to identify all studies published before May 2011 that reported public attitudes toward epilepsy. The Boolean search using “(attitude*[Title] OR stigma[Title]) AND epilepsy” were performed. Additional search using specific MeSH subheading “health knowledge, attitudes, practice” was used to widen the scope of the search strategy.

Inclusion and exclusion criteria

A study was included if it reported the public or patients’ attitudes towards epilepsy, regardless of its targeted respondents. Studies using qualitative methodology were not excluded. Papers written in languages other than English were excluded in the search. Case reports, review articles, meeting abstracts, brief communications, and non-journal articles were excluded.

Study selection

All abstracts were independently reviewed by the two reviewers to determine if they met eligibility criteria. Any study identified by either reviewer was included. The full text articles of eligible abstracts were then reviewed independently by both reviewers to determine final eligibility for data abstraction. Disagreements were resolved by discussions between the reviewers. Additional papers were identified and gathered manually by searching the reference lists of all included articles.

Data extraction and analysis

The data for all eligible articles were then independently abstracted by both reviewers using a standardized form including variables such as the sample size, target respondents, year of publication, country, and continent. Additional variables including the percentage of negative attitudes toward marriage, employment and social contact were screened and tabulated. Descriptive statistics including frequency and percentage were used in analysis. The association between public attitudes towards epilepsy and the standard of living in a country was examined. Gross domestic product (GDP) per capita is a good indicator of standard of living in a country. GDP per capita for the year 2010 was thus used in this comparison, and obtained from World Economic Outlook Database-April 2011, International Monetary Fund.

RESULTS

Three hundred and thirty one abstracts were identified from the initial search with 129 full text articles meeting all eligibility criteria. These included 119 full text papers and 10 abstracts without full text papers from regional journals, e.g. Ethiopia Medical Journal and West Africa Journal of Medicine, all of which were selected for data abstraction. Three additional papers were identified from the reference lists and included. In total, 132 relevant articles from 50 countries were identified, as demonstrated in Figure 1.

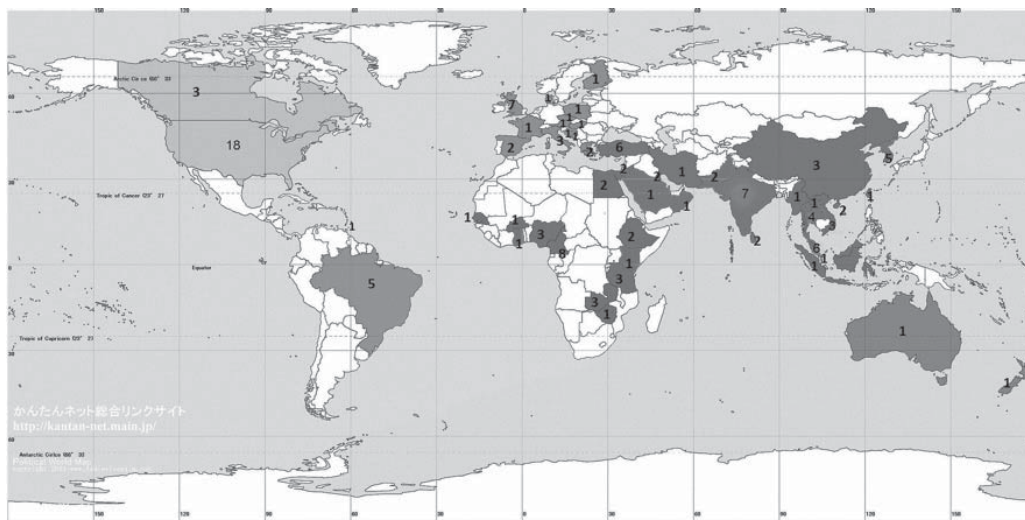


Figure 1. Countries with publications on public attitudes toward epilepsy (n=50). The numbers represent the number of papers published in each country.

History

The first questionnaire on public attitudes towards epilepsy was designed by Caveness in 1949 using a Gallup poll in the US, and consisted of 10 questions on the knowledge, attitude and practice in epilepsy.⁸ Four questions were asked regarding attitudes toward epilepsy, including social contact (e.g., “Would you object to having any children in school or at play associate with persons who sometimes had seizures (fits)?”), employment (e.g., “Do you think people with epilepsy should or should not be employed in jobs like other people?”), marriage (e.g., “Would you object to having a son or daughter of yours marrying a person who sometimes had seizures?”), and perception (e.g., “Do you think epilepsy is a form of insanity or not?”).

The study by Caveness on public attitudes towards epilepsy was subsequently repeated, modified, and quantified in various countries across the 6 continents, as in Figure 1 and 2, and carried out in various languages including Malay¹⁵, Thai¹⁶, Vietnamese¹⁷⁻¹⁹, Chinese^{18,20-22}, French²³, Turkish²⁴, Spanish²⁵, Lao language²⁶, Malayalam language^{27,28}, Swahili language²⁹, and Urdu language.³⁰

The first paper in Europe was published in 1974³¹, followed by Asia in 1984, Africa in 1991³², Australia in 1994³³ and South America in 1998.³⁴ There was an exponential increasing trend in the number of publications after 1990,

especially in Asia and Africa, resulting in the highest number of publications in Asia (52/132, 39.4%), followed by Africa and Europe (21.2% and 17.4%, respectively).

Taking attitudes towards epilepsy as a mean for comparison, public attitudes towards epilepsy was compared. Across time, Caveness demonstrated that attitudes in the United States improved over 30 years (1949-1979), as shown by the black dots in Figure 3 before 1970.⁸⁻¹⁴ Hicks also reported a similar positive trend in employment in United State of America (USA) over 30 years (1958-1988).³⁵ However, there were no studies demonstrating a similar trend in attitudes in other continents, with Asia and Africa showing a significantly worse trend instead, as shown in Figure 3.

Attitudes towards epilepsy and the associated factors

Factors associated with negative attitudes towards epilepsy

Attitudes towards epilepsy can be influenced by the individual’s socioeconomic background, knowledge, and the illness perceptions of epilepsy. People from rural areas with lower educational level and socioeconomic status have been found to have more negative attitudes towards epilepsy.^{15,16,20,22,32,34,36-39} Other factors include old age^{19,47,48,50}, male gender^{22,36,37}, female gender³⁸,

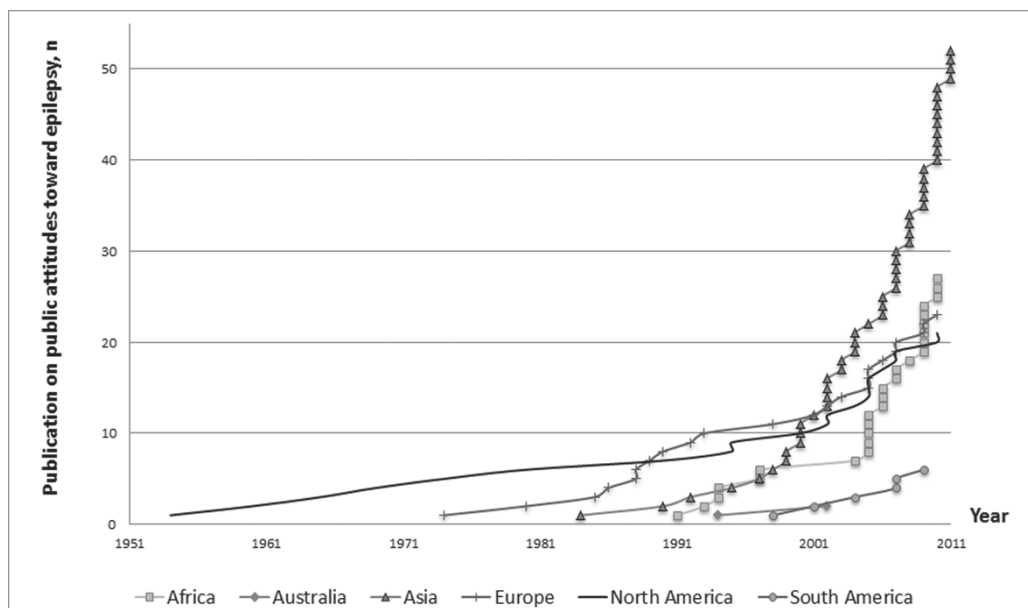


Figure 2. Publications on public attitudes towards epilepsy (n=132 papers)

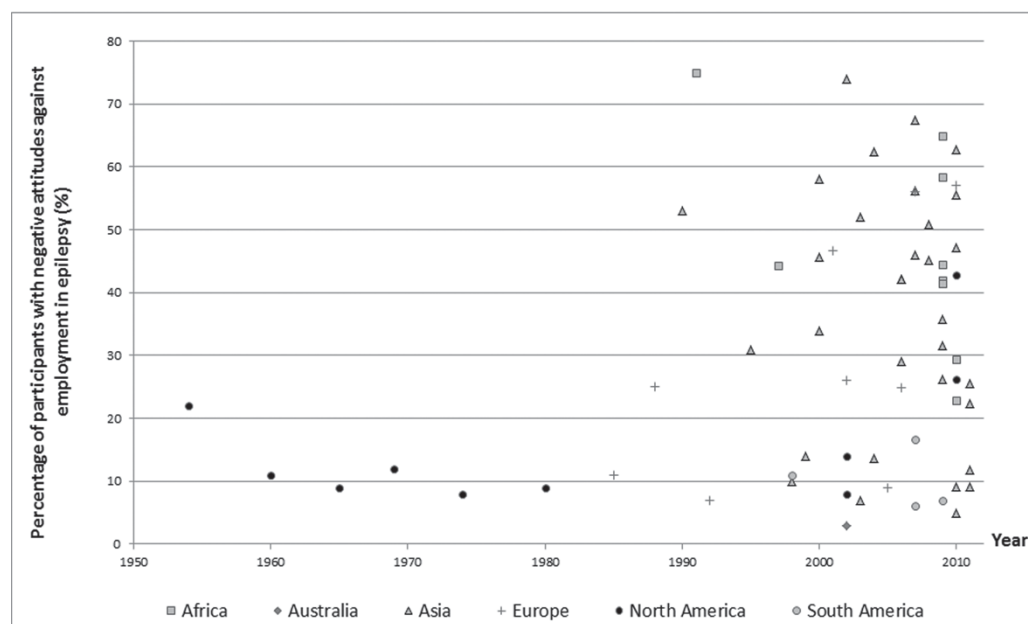


Figure 3. Negative attitudes against employment in epilepsy, according to geographical distribution and year (n=66 papers)

being single²², and Hindu ethnicity.⁴⁰

Knowledge about epilepsy is an important factor in reducing the degree of discrimination and negative attitudes toward epilepsy. Studies show that people with less knowledge about epilepsy, or without personal contact with someone with epilepsy, have poorer attitudes.^{15,16,20,34,36-39} The magnitude of the negative attitudes seems to be aggravated by the presence of misconception of epilepsy, which include the perception of epilepsy as a form of insanity^{16,37,20}, being untreatable^{36,41}, contagious³⁰, hereditary⁴¹, or a form of mental retardation.²⁰

Attitudes toward epilepsy across continents

The studies in Northern America, in general, demonstrate more positive attitudes towards epilepsy, as shown in Figure 3. However, direct comparison and statistical analysis could not be performed as these papers utilized different questions and target populations. Interestingly, Chung studied the attitudes of Chinese and Vietnamese adults in the United States, and found a higher percentage of negative attitudes against employment in epilepsy as compared to the earlier studies by Caviness (43% vs. 8-22%).^{9-14,18}

Asia and Africa are the two continents with the worst attitudes against employment in epilepsy, where 50.0% (16/32) and 80.0% (8/10) of the

published papers respectively reported more than 40% of participants with negative attitudes, as compared to none in North and South America, and Australia, except the study by Chung on Asian migrants in the United States.¹⁹ Studies in South America were however only limited to Brazil and Trinidad & Tobago.

Publications in Europe showed mixed results where two papers in Italy and one in Hungary reported high percentage of participants with a negative attitude towards employment in epilepsy (56%, 57% and 47%, respectively).^{38,42,43}

Attitudes towards epilepsy and standard of living

Figure 4 shows that in general, the magnitude of negative attitudes towards epilepsy is inversely proportional to the GDP per capita, except in Italy and Kuwait^{38,42,44}, countries with a high GDP per capita and a high percentage of negative attitudes towards epilepsy (circled in figure 4), and in Turkey, Brazil, India and the Chinese in Malaysia^{20,34,45,49}, countries with a low GDP per capita and a low percentage of negative attitudes towards epilepsy (squared in figure 4).

Study design

Variability in the questions

Some questions have been phrased in the form of

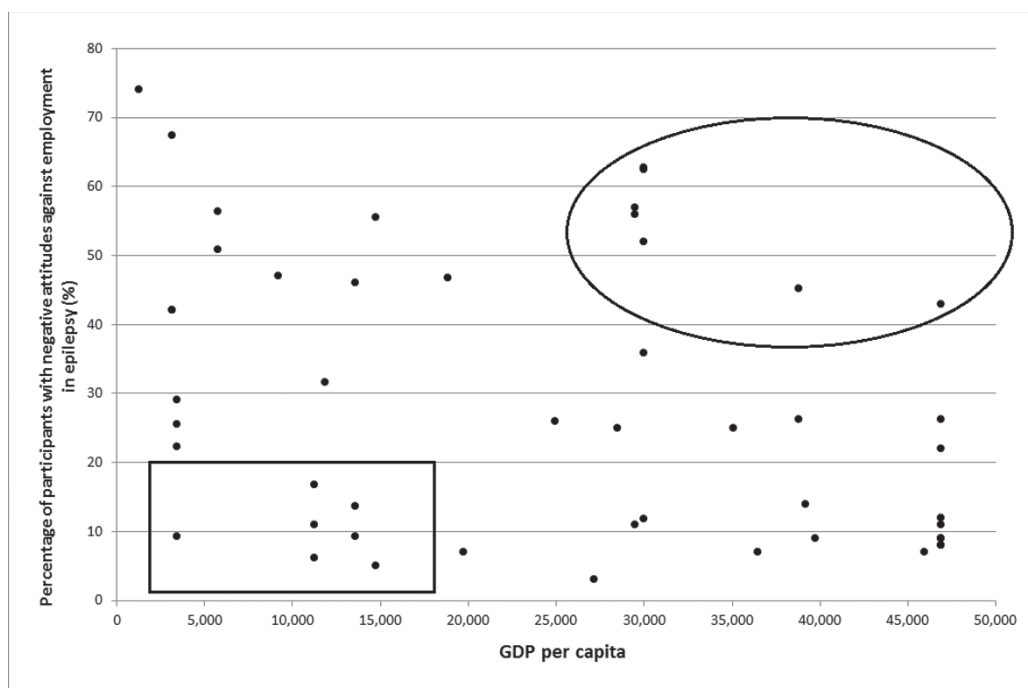


Figure 4. Negative attitudes against employment in epilepsy, according to gross domestic product per capita, based on papers published in 2001-2011 (n=47 papers). Countries with high GDP per capita with poor attitude are circled, and the opposite are squared.

a general statement (as shown in Table 2), whereas some questions required personal consideration, for example a marriage involving the participants or their children.

Most of the questions were phrased negatively, e.g. using the words “object”^{14,19,37,50-55} and “should not”⁵⁶. Some phrased the statement in a neutral tone, while others positively (e.g., “can”²³ and “allow”⁵⁷⁻⁶⁰).

Some questions asked in greater detail, for example, it was specified as “marry a girl” or “marry a man” in questions on attitudes against marriage⁵⁷⁻⁶⁰, and in regards to employment participants were requested to consider the types of occupation.^{20,39}

Terminology used also varied, in which the term “epilepsy” was most commonly used, though the words “seizures or fits”⁹ used by Caviness were subsequently used in many other studies.^{18,46,52-58}

Variability in study populations

Half (52.5%) of the studies were carried out within the general population, followed by 13.3% amongst teachers and students respectively. Ten papers reported the attitudes of health care providers, mostly general practitioners, but also

included physicians, nurses, and psychiatrists; two studies were carried out amongst caregivers, and one amongst employers, clerics and police.

Some of the countries performed the studies within the general population as well as within a specific group, allowing indirect comparisons to be made. Using the percentage of participants with negative attitudes towards social contact in epilepsy as a mean of comparison, Table 4 shows that students had better attitudes towards epilepsy in most countries, except Turkey. Teachers had better attitudes in Thailand and Turkey^{18,45}, but conversely in India.⁶¹

Attitudes towards epilepsy when compared between people with epilepsy and their family members⁷⁸ showed that there were no significant differences in attitudes between the two groups. When compared to general populations⁶², people with epilepsy had better attitudes toward epilepsy.

Quantitative and qualitative approaches

Questionnaires using a scale enabled the measurement of the attitudes towards epilepsy in a quantitative manner. Ten studies used either Likert’s scale or a scoring system to measure

Table 1: Examples of questions on attitudes towards marriage in epilepsy

<p>General Statement</p> <ul style="list-style-type: none"> • Do you think it is appropriate for a person with epilepsy to get married?⁴⁵ • Should people with epilepsy get married?¹⁸ • Would you agree to people with epilepsy getting married?⁷⁵ • People with epilepsy should not marry.⁵⁶ • I believe people with epilepsy should not marry.⁶⁴ • Do you think that epilepsy is an important impediment for marriage?⁴² • How much does epilepsy limit marriage?³⁸
<p>Personal consideration of marriage involving the participants themselves</p> <ul style="list-style-type: none"> • Would you be willing personally to marry someone with epilepsy?⁷⁶ • Would you marry a person with epilepsy?^{45,47} • Would you agree to marry (yourself or your children) with him/her provided this person is otherwise acceptable?^{20,62,68}
<p>Personal consideration of marriage involving the participants' children</p> <ul style="list-style-type: none"> • Would you object to having a son or daughter of yours marrying a person who sometimes had seizures (fits)?^{9,11,14,19,22,37,50-55,77} • Do you allow your son to marry a girl with epilepsy?⁵⁷⁻⁶⁰ • Do you allow your daughter to marry a man with epilepsy?⁵⁷⁻⁶⁰ • Would you object to a person with epilepsy marrying a close relative of yours (brother, sister, or child)?^{78,79} • Would you object to your child getting married to a person with epilepsy?¹⁸ • Would you object to your son or daughter marrying a person with epilepsy?⁴⁴ • Would you allow your children to marry people with epilepsy?^{41,61,75} • My child can marry a people with epilepsy.²³ • Would you agree to marry (yourself or your children) with him/her provided this person is otherwise acceptable?^{20,62,68} • Would you approve if your son/daughter married a person with epilepsy?⁴⁵ • I would object to the marriage of my child with someone who has epilepsy.⁴⁶

attitudes towards epilepsy.^{15,46,62-69} The scales, that had been developed or adapted from previous scales, included the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale⁷⁰, the Attitudes Toward Persons with Epilepsy (ATPE)^{63,71}, the Epilepsy Attitude Scale⁴⁶, and the Elementary School Epilepsy Survey (ESES)⁶⁷ for elementary school children. Although there were significant overlaps between the scales, there were also differences in questions, subscales, number of items, and scoring system.

One study in Africa used a qualitative approach (n=200) and provided new insight into some of the aspects of attitudes that would otherwise remain undetected using structured questionnaires, including attitudes such as tolerance, kindness, and sympathy towards people with epilepsy.⁷²

Intervention studies

Five intervention studies using educational

programs, personal contact, or educational material about epilepsy showed that besides an improvement in the knowledge about epilepsy, there was also significant improvement in the attitudes towards epilepsy.^{24,36,47,73,74}

DISCUSSION

Attitudes towards epilepsy and the associated factors

This study describes the prevalence and variability of public attitudes toward epilepsy. The variation of attitudes across geographical regions are likely multifactorial. In medical anthropology, the Western Civilization is viewed as depending mostly on a naturalistic explanation of illness. This probably minimizes the misconception and stigma in epilepsy, which may lead to better attitudes. In contrast, geographical regions with strong cultural perception of disease that rely on non-scientific explanation, e.g. Asia and Africa have

Table 2: Examples of questions on attitudes towards employment in epilepsy

<p>General statement</p> <ul style="list-style-type: none"> • Equal employment opportunities should be available to individuals with epilepsy.⁶³ • Do you think people with epilepsy should or should not be employed in jobs like other people?^{9,11,14,19,22,37,50-55,77} • Do you think that, in general, persons with epilepsy should be employed at the same jobs as other people?^{53,78,79} • Do you think that epilepsy patients can be employed?²⁸ • Do you think that epilepsy is an important impediment for a job⁴²
<p>Personal consideration as an employer</p> <ul style="list-style-type: none"> • I would object to hiring someone who has epilepsy.⁴⁶ • Would you employ someone with epilepsy?⁴⁷ • Would you employ an epileptic?³² • Are you going to hire a person with epilepsy if you are an employer?⁴¹ • If you were an employer, would you hire people with epilepsy?^{44,75} • If you are an employer, do you allow a patient with epilepsy to be your employee?⁵⁷ • If you were an employer, would you knowingly hire someone with epilepsy?¹⁸ • As an employer, would you hire a person who is subject to epileptic seizures?⁸⁰ • Would you hire him/her in your own business provided he-she had the skills or qualifications for it?^{62,68} • Assuming you had a business of your own, would you hire an epileptic in your own business, if he/she has the skills or qualifications for it? ²⁰ • If you were an employer, would you terminate the employment of persons with epilepsy, if a seizure occurred during work because of unreported epilepsy?¹⁸
<p>Personal consideration in relation to a specific job (with a choice of jobs including teacher, nurse, doctor etc.)</p> <ul style="list-style-type: none"> • Would you be willing personally to employ someone with epilepsy in a clerical job?⁷⁶ • What jobs do you think epileptics should not be employed in?^{20,57} • Which, if any, of the following jobs do you think people with epilepsy should not be employed in?³⁹

poorer attitudes towards epilepsy. In addition, Western philosophy with emphasis on basic human rights could be another explanation for better attitudes in Western countries. Even though non-scientific influence on disease perception is still predominant in Asia and Africa as evidenced by the misconception of epilepsy as spiritual, contagious and a form of insanity, modern scientific education and political emphasis on basic human rights might have a positive impact on these misconceptions. However we have yet no historical data to prove the above.

The inversely proportional relationship between the magnitude of negative attitudes towards epilepsy and the GDP per capita (Figure 4) might be indirectly related to modern education and emphasis on human rights, or directly related to economic status. As evidenced in many studies demonstrating better attitudes in urban population compared to rural population in the same region, economic status has a direct impact on attitude

towards epilepsy. However, there are exceptions as shown in Figure 4, where the economic status is not the only variable explaining the variation in public attitudes.

Factors associated with negative attitudes towards epilepsy have been extensively examined. These include socioeconomic status, knowledge and education level, perception and misconceptions. However, we are uncertain about the actual reasons behind such negative attitudes. For example, a community that emphasizes a family's honor may be more likely to object to marriage with people with epilepsy as compared to a community that emphasizes freedom of choice in marriage. Therefore, the cultural values molding the attitudes should be explored qualitatively. The study by Chung, which reported a higher percentage of negative attitudes against employment in epilepsy in the Chinese and Vietnamese adults in United States as compared to American adults (43% vs. 8-22%)^{9-14,18}, suggested that cultural influence

Table 3: Comparison of the attitudes against social contact between the community, students and teachers, according to country

Country	Percentage of participants with negative attitudes against social contact in epilepsy*		
	Community (%)	Students (%)	Teachers (%)
Cameroon	15.9-51.4 ^{54,81-83}	14.6-37.9 ⁸⁴⁻⁸⁶	
India	5.0-10.8 ^{28,49}	13.0-15.6 ^{27,87}	38.4 ⁶¹
Korea	18.1-50 ^{36,41,62}		32.1 ⁷⁵
Kuwait	27.6 ⁴⁴	12.5 ⁷⁶	
Tanzania	51.0 ²⁹	46.0 ⁸⁸	
Thailand	17.3 ¹⁶		2.8 ⁸⁹
Turkey	28.0 ⁵¹	53.2 ²⁴	6.3 ⁴⁵

*Questions on attitudes against social contact, e.g. “Would you object to your children associating with people who sometimes had seizures?” were asked in the included studies. The percentages quoted were the percentage of the participants who gave a negative response to these questions.

on public attitudes towards epilepsy might not be easily changed merely through geographical migration.

Study design

Questionnaires varied depending on the population studied, and the local cultural context and personal preferences, creating great difficulty in directly comparing published study results. A general statement tended to produce more positive results, giving a false impression. Questions which required personal consideration, either a marriage involving the participants or their children, were more reflective of the actual stigmatization, and this tended to skew the results negatively. In general, negatively phrased statements encouraged negative attitude as disagreeing with a negatively phrased statement is cognitively a complex task. Furthermore, statements which emphasized parental authority, e.g. “Would you object to having a son or daughter of yours marrying a person who sometimes had seizures (fits)?” may not be appropriate in a society that emphasizes freedom of choice; whereas statements using the word “can” assessed purely the personal perception of one’s suitability to work or marry, without taking the parental authority into account. Questions asked in greater detail, such as questions related to specific occupation, though providing the understanding of the discriminating factors like gender and types of occupation, might have excessively prolonged the survey.

Surveys on epilepsy patients allow us to determine the discrepancy between patients and the general population in knowledge and perception towards epilepsy. The degree of discrepancy will indirectly indicate the magnitude of social stigma in the studied population. Therefore, direct comparison of attitudes towards epilepsy between epilepsy patients and the public should be encouraged.

Previous studies had provided a way to measure public attitudes, either through a questionnaire or a scale, but lack of standardization of the study design made direct comparison among various studied populations difficult. A quantitative scale is essential and practical to provide an overall picture of attitudes in a selected study population, and allows for comparison among different populations. Furthermore, this approach allows monitoring of changes over time, as well as measuring the outcome of an intervention. However, none of the scales were widely accepted as a gold standard. Thus we should aim to develop a standardized, quantitative, and cross-cultural measure of public attitudes toward epilepsy for cross-sectional and longitudinal comparison.

Although there are specific questions dealing with a specific issue (e.g., employment), the results might not reflect the actual concerns of the community and employers, and the challenges faced by people with epilepsy. Therefore, qualitative assessment of the concerns and challenges should be encouraged.

Interventional studies have shown that education

on epilepsy could improve attitudes in a studied group. These results reinforced the importance of public education in reducing the stigma of epilepsy. Furthermore, this interventional design might be effective in determining the usefulness of epilepsy awareness campaign in changing public attitudes. However, we are uncertain of whether improvement in socioeconomic status and education level of the population will translate into an improvement in public perception and attitudes towards epilepsy. Longitudinal studies in multiple regions are required to answer this uncertainty.

Most studies on attitudes are designed from a human rights perspective, to determine whether the patients are being discriminated against. Other attitudes such as overprotection, empathy and tolerance, are equally important. For example, overprotection of children with epilepsy may affect their personality development. Therefore, future studies should also aim at greater understanding of these attitudes.

It is a methodological challenge to study how public attitudes might impact life of people with epilepsy. However, if we are unable to determine this relationship, we will face a bottleneck in research of public attitudes toward epilepsy.

Thus, studies on attitudes should be conducted continuously, particularly in populations prone to have negative attitudes with emphasis on underlying reasons, and progress should be monitored longitudinally. Attitudes of people such as parents, teachers, school counselors, health care professionals, and employers, which have direct impact on people with epilepsy, should be more extensively studied.

Limitations of the study

This review only included studies presented in English, as it is limited by the inaccessibility of journals written in other languages and the inability to interpret the results without translation. Nonetheless, as shown in Figure 1, the information about public attitudes towards epilepsy was available in most countries in each continent, except Africa and South America.

Conclusion

Since 1949, public attitudes towards epilepsy had been extensively studied with an exponential increase in publications in the past twenty years. However, the increase in number of published studies did not lead to improved quality of care for people with epilepsy. This review presents

the background, development and progression of research on public attitudes toward epilepsy, focusing on the status of attitudes across time and geographical regions, its associated factors, as well as the study design, aiming to provide a guide for future study.

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