

A Review of Epilepsy Stigma in Egypt

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Abstract

Objective: Epilepsy is the most common serious neurological disorder worldwide, affecting 50 million people. Epilepsy is one of the most stigmatizing disorders worldwide and a prototype for a stigmatizing disorder with its dramatic and often scaring symptoms and signs. In this review, I discuss the following definition; stigma and discrimination; historical background; factors affecting stigma; how to decrease the stigma of epilepsy and burden of stigma and conclusion.

Result: People with epilepsy (PWE) devalued and stigmatized. False historical background, uncorrected knowledge and attitude about epilepsy, psychosocial factors of epilepsy and uncontrolled epilepsy lead to stigma of epilepsy. The factors affect stigmas are false historical background of epilepsy, psychological aspects of epilepsy, knowledge, attitudes towards patients with epilepsy, uncontrolled epilepsy and effect of Antiepileptic drugs.

Significance: To proper manage of epilepsy, we should know the factors lead to stigma. Stigma of epilepsy has impact effect upon patients, relatives and society.

Keywords: Epilepsy; Stigma; Knowledge; Attitude; PWE; Psychological aspect

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Introduction

Epilepsy is the most common serious neurological disorder [1]. It knows no geographical, racial, or social boundaries. The etiology of seizures is multi factorial in any given person [2]. Epilepsy is as an interaction between genetically determined seizure threshold, underlying predisposing pathologies or metabolic derangements, and acute precipitating factors [3].

Epilepsy is one of the most common neurological disorders with a worldwide prevalence between 5 and 10 per 1000 with considerable variations between different settings [4, 5]. In Egypt, the prevalence was 6.98 / 1000 [6].

It became clearer that people with epilepsy are socially discriminated against on the ground of wide-spread lack of knowledge, negative public attitudes, and misconceptions about the disease. The social problems met by students with epilepsy as a result of negative attitudes and beliefs are enormous and the attitude and knowledge of teachers on adulthood epilepsy where that is likely to influence the educational performance of students with the disease [7].

What is Stigma?

The word stigma derived from the Latin *stigmata*, means "mark" or "brand" and from the Greek *stizein*, "to tattoo." Stigma defined

as a brand, a mark of shame or discredit, a stain, and an identifying mark or characteristic. Stigma is a large part of the burden carried by people with epilepsy [8]. Stigma is a social process that is observed when there are elements of labeling, stereotyping, and discrimination because of previously specified characteristics as different and unacceptable, which result in social status loss [9]. Weiss et al. [10] suggested that stigma characterized by a personal experience of rejection, exclusion, accusation, and depreciation, which is a result of experience or a reasonable expectation of a negative social assessment of a person or a group. Health-related stigma based on a special characteristic of a health problem or a status as the existence of stigmatization is being due to fear of seizures and due to inadequate education on the special features of the disease or on administering first aid during seizures [11].

Factors Affecting Stigma with Epilepsy

Historical misconception of epilepsy

The epilepsy-related stigma has a long ancestry. From the earliest times of civilization, epilepsy has been associated with many misconceptions, blame, and discrimination to each patient and often of their families. A reason for this is that epileptic seizures are sudden events that come out of the blue with often bizarre behavioral and physical symptoms and convulsions. Basic concepts of epilepsy were known from the ancient Indian medicine of the

Vedic period of 4500–1500 BC, but the main descriptions of the disease are mainly dated from 2000 BC. Epilepsy viewed as supernatural, demonic, magical, or contagious.

Real advance in understanding epilepsy made by Hippocrates (460–370 BC) in ancient Greece who in his famous treatise “on the sacred disease” clarified that epilepsy was just a natural disease of the brain no more divine and no more sacred than other diseases. Unfortunately, misinterpretations have continued for many centuries; people with epilepsy have viewed with fear, suspicion, and misunderstanding and were subjected to enormous social stigma including punishments such as outcasts and death. For example, epileptic seizures described as characteristic features to identify witches in *Malleus Maleficarum* (1486), a judicial handbook of witch-hunting written by two Dominican friars under papal authority that led to persecution, torture, and death of more than 200,000 women in over 300 years.

Only in the nineteenth century, the scientific concept of epilepsy as a brain disorder became more widely accepted, especially in Europe and the USA, but again patients with epilepsy continued facing significant discrimination. Widespread ignorance, fear, misunderstanding, and stigma contributed to severe legal and social penalties.

In Germany, during the Third Reich, a “Law for the Prevention of Offspring with Hereditary Diseases” came into effect in 1934 forcing compulsory sterilization and extermination of people with hereditary disabilities. Epilepsy included as a “hereditary falling disease.” People with epilepsy were the victims of eugenic sterilization programs in Sweden (1935–1975), many states of the USA (until 1956), and were not allowed to marry (in the UK until 1970).

The complex familial inter relationships of the Pharaohs Tuthmosis IV, Amenhotep III, Akhenaten, Smenkhkare and Tutankhamun. A complete analysis of all the data available to-date, which includes historical, artistic and medical sources, reveals a pattern of early deaths and disease in these XVIIIth dynasty rulers of ancient of Egypt due to a familial temporal epilepsy syndrome which considered as abnormal behavior [12].

Psychological aspects of epilepsy

Epileptic activity within the brain has an effect on the behavior, mood, and cognitive functions of the epileptic patient. Additionally, his / her behavior and mood may be affected by the attitude of others to his / her disability. Furthermore, the patient’s social and psychological adaptations may change his / her epileptic experiences. As a consequence of the interaction between these aspects patients with epilepsy face many cultural and psychosocial problems [13].

Patients (seventy-one male patients with idiopathic epilepsy), reported highly significant impairment in all cognitive measures and higher scores on depressive symptoms, aggressive behavior, and most personality traits compared with controls (58 subjects matched with respect to age, sex, and socioeconomic status) in study were recruited from the outpatient epilepsy clinic of Assiut University hospitals. Epilepsy itself and epilepsy-related factors such as Early age at onset, prolonged duration of illness, increased

frequency of seizures, and history of status epileptics associated with cognitive function deterioration, depression, aggression, and some abnormal personality traits [14].

Knowledge, attitudes towards patients with epilepsy

It has become clearer that people with epilepsy are socially discriminated against on the ground of widespread lack of knowledge, negative public attitudes, and misconceptions about the disease. Knowledge, perceptions and attitudes towards epilepsy investigated among patients [15, 16], health service providers [17-19] and public [20-23] in different settings.

A cross-sectional study was made among guardians (parents / guardians) of high school students in Assiut city, Egypt. A 15-item questionnaire was self-administered by 1257 student’s guardians who were randomly selected. All recruited parents / guardians of high school students heard about epilepsy. Families with a patient with epilepsy (PWE) had significant better information about epilepsy and its etiology than other families. The predictors of negative attitudes towards PWE were: age group ranging from 40 to 49 years, no work, skilled work, male sex and incorrect knowledge [24].

A cross sectional study applied among secondary schools teachers in Assiut city, Egypt. A 12-item questionnaire was self-administered to 189 teachers, who selected randomly. All teachers heard about epilepsy. About 46% of teachers dealt with students with epilepsy as abnormal students. About 46.6% of the teachers stated that the epileptic student was a source of “problems” in the classroom. Also, 9.6% would like the student to be transferred to another school either because his or her presence is considered as an “too much of a responsibility for the teacher” or “is negative for other students by any mean as interruption of the educational process. Only one quarter (23.8%) of teachers accepted to give student with fit in the class first aid measures and 12.7% accepted to give the student, who had a seizure in the class any form of prescribed treatment. Positive attitudes were common among females and single teachers [6]. Teachers knowledge about and attitudes towards epilepsy have direct impact on students with epilepsy in terms of school performance, social skill development, and post school success in the areas of employment, social skills, and social network development [25, 26].

Students with epilepsy cope with the discrimination by peers that often follows seizures at school [27]. They often report feeling different from their peers and are fearful of having seizures in front of their friends, resulting in adjustment problems including poor self-esteem [28]. Educating students about epilepsy is an important step in alleviating the stigma faced by students with epilepsy at school. Furthermore, students are the future workforce of the country and have the potential to become role models for society [29].

Another cross-sectional study applied among secondary school students in Assiut city, Egypt. A 13-item questionnaire was self-administered by 2226 students who selected randomly. Only 7.1% of epileptic students and 8.5% of non-epileptic students thought that the epilepsy is a brain disease. Out of 2198 non-

epileptic students, 28.4% thought that person with epilepsy (PWE) should not marry and 92% of them refused to marry from PWE. The correct knowledge of epilepsy was significant positive correlated with positive attitude towards PWE. However, students still feel persons with epilepsy are stigmatized and are different from others. Secondary school students in Egypt had a vague knowledge about the etiology of epilepsy. Misconceptions about and negative attitudes towards epilepsy were unexpectedly high among those students [30].

In agreement with our earlier studies [6, 24, 30] Rho and his colleague [31] found that the factors contributing to stigma - related perceptions of epilepsy were lower level of knowledge about this condition, and lower level of education. A clear relationship observed between level of education and an individual's familiarity with and attitudes toward epilepsy [32]. Also, Saengsuwan [33] four factors associated with the knowledge about epilepsy, included education level, age, epilepsy duration, and a history of experiencing antiepileptic's medication side effects.

Uncontrolled epilepsy

Although the prognosis for most patients with epilepsy is good [34], up to 30% of patients do not experience remission despite right therapy with antiepileptic drugs [35]. This situation has real deleterious effects on patient health and quality of life and places a heavy burden on society. The study carried out in 3 states via door-to-door screening of the total population (62,583 persons) at El Kharga, New Valley, Egypt. All suspected cases of epilepsy subjected to case ascertainment, conventional Electro - Encephalography (EEG), and the Stanford-Binet Intelligence Scale. Patients received suitable anti-epileptic drugs (AEDs) over the past 6 months and had active seizures, considered as uncontrolled. Fifty age and gender-matched patients with controlled epilepsy chosen for statistical analysis and compared with true intractable patients. A total of 437 patients with epilepsy identified, 30.7% of whom ($n = 134 / 437$) were uncontrolled, with a prevalence of 2.1 / 1000. A total of 52.2% of uncontrolled patients ($n = 70 / 134$) were inappropriately treated, while 47.8% ($n = 64 / 134$) were compliant with appropriate treatments. Video monitoring EEG of compliant uncontrolled patients demonstrated that 78.1% patients ($n = 50 / 64$) had definite epilepsy, while 21.9% ($n = 14 / 64$) had psychogenic non-epileptic seizures (PNES). A logistic regression analysis revealed that status epilepticus, focal seizures, and mixed seizure types were risk factors for intractability [36]. Uncontrolled epilepsy leads to more stigmatization upon patient with epilepsy.

Effect of antiepileptic drugs

Antiepileptics drugs (AEDs) have both negative and positive effects on cognition and behavior [37]. AEDs are able to improve cognition and behavior, which has been attributed to reduction of seizure activity, and modulating effect on neurotransmitters and their psychotropic effect. AEDs reduce neuronal irritability and increase postsynaptic inhibition or alter synchronization of neural networks to decrease excessive neuronal excitability associated with seizure development and secondary spread of epileptic activity to the surrounding normal brain. However,

excessive reduction of neuronal excitability may result in slowed motor and psychomotor speeds, and poor attention and memory processing, which are common side effects of sodium channel blockade and increasing GABAergic inhibitory activity [38]. It is not surprising that patients with epilepsy are more susceptible to the adverse behavioral effects of AEDs than other populations, possibly due to the disease associated structural or functional changes that increase their risk of psychiatric disorders and that lead to more stigma.

In our previous study was carried out in Assiut university hospital, outpatient clinic of epilepsy cognitive, mood, behavior and personality traits were assessed in 45 epileptic patients treated with carbamazepine and / or valproate and free of seizures for 1 year. Thirty four newly diagnosed or untreated patients with epilepsy and 58 matched healthy subjects were also included for comparison. A battery of psychometric tests was utilized including Stanford-Binet (4th edition), Beck Inventory for Depression, Aggressive Scale and Eysenck Personality Questionnaire. Compared to matched control subjects, treated and untreated epileptic patients had poor performance in different cognitive and behavioral functions testing. Treated patients had worse scores in memory for digits forward and backward, total short-term memory, extroversion and psychosis. The duration of AEDs intake was correlated with memory of objects ($r = -0.323$; $P = 0.030$), bead memory ($r = -0.314$; $P = 0.036$) and total nonverbal short-term memory ($r = -0.346$; $P = 0.020$). Treated and untreated epileptic patients had poor performance of similar extent in behavioral functions testing (depression, aggression and neurosis). The dose of AEDs was correlated with testing scores for neurosis ($r = 0.307$; $P = 0.040$), verbal aggression ($r = 0.483$; $P = 0.001$) and nonverbal aggression ($r = 0.526$; $P = 0.000$), and duration of drug intake was correlated with scores for depression ($r = 0.384$; $P = 0.009$), psychosis ($r = 0.586$; $P = 0.0001$) and nonverbal aggression ($r = 0.300$; $P = 0.045$) [39].

Economic Burden of Stigma of Epilepsy Upon patient with epilepsy and family

Stigma affects epilepsy patients in a variety of ways. Stigma of epilepsy worries the patient more than the disease itself, makes the patient feel guilty, mental status impairment, and is associated with depression. In persons with epilepsy, stigma is a result of the unpredictability of seizures and social exclusion due to a negative attitude of society, including difficulties in education, having a family, and finding a job, even when not contraindicated. Because of stigmatization, patients hide the disease from relatives, partners, and employers [40].

Lower marriage rates for men and women with epilepsy are partially attributable to stigma of having epilepsy [41, 42]. Zahn reported that 51% of men with epilepsy were married, in contrast to 63% of men without epilepsy. Likewise, only 48% of women with epilepsy were married, compared with 59% of women without epilepsy. Limited social opportunities contribute to lower birth rates among men and women with epilepsy [43]. In addition, patients refused to marry their offspring from PWE [6, 24, 30].

Stigma may also affect patient's health by impacting access to care and by contributing psychosocial stress to the physiological burden of disease. Employment discrimination is a reality for many individuals with epilepsy. Although the Americans with Disabilities Act (ADA) was initially thought to address many of the discriminatory employment practices adversely impacting persons with epilepsy, recent judicial rulings suggest that persons with epilepsy have little protection against unreasonable employment practices [44].

Quality of life in individuals with epilepsy is negatively impacted by the stigma surrounding the condition. A recent study by Suurmeijer et al. [45] used questionnaires to assess health perceptions and social/psychological functioning of 210 epilepsy patients from four outpatient clinics in The Netherlands. These patients identified psychological distress, loneliness, adjustment and coping, and stigma perception as the most important influences on their quality of life. These perceptions did not vary between patients with mild epilepsy and those with more severe epilepsy.

Upon society

Epilepsy was estimated to account for 0.5% of the global burden of disease, accounting for 7 307 975 disability adjusted life-years, in 2005 [46]. These figures did not take into account the limited data from the low income or that the disability weights of epilepsy are not based on measurements in poor areas. Deriving accurate figures on the epidemiology of epilepsy in low income is very difficult since most data have to be derived from cross-sectional surveys, of which there are few and which are expensive to undertake. In high-income countries, accurate population denominators from regular country-wide censuses and the identification of incident and prevalent cases of all types of epilepsy through well-established medical records systems allow accurate estimates to be evaluated.

The global burden of epilepsy, includes physical hazards resulting from the unpredictability of seizures, social exclusion as a result of negative attitudes of others toward people with epilepsy and the stigma, as 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 [47].

How to Minimize the Stigma of Epilepsy

Improving knowledge and attitude against epilepsy

Uncorrected knowledge and negative attitudes towards PWE are generally very positively affected on person with epilepsy. However, there is still a feeling among the population that persons with epilepsy are stigmatized, and this is most apparent among groups that may experience discrimination. This study is important in providing baseline information about the psychosocial aspects of epilepsy in the region and also highlights the need for further and more coordinated efforts to educate all population, students and teachers about epilepsy [6, 24, 30].

Increasing the awareness about epilepsy and its etiology will raise the level of knowledge and improve the attitude towards a PWE [24].

Lowering social stigma may significantly help to improve the quality of life of children and adolescents suffering from epilepsy [48]. Stigma may be lowered by various educational programs focused on increasing awareness and knowledge about epilepsy. The effectiveness of various types of educational programs was examined in the past with varying results [49, 50]. One of the effective ways to reduce disease-related stigma is to utilize educational video. This technique has been tested successfully on diseases such as schizophrenia [51] and other psychological disorders. Educational videos were successfully used in the field of epilepsy as a tool to improve the knowledge of undergraduate students of psychology and to reduce epilepsy related stigma in this target group. It has been found that it is usually more difficult to achieve changes in attitudes towards patients with epilepsy than to increase knowledge about the disease [52].

The effect of religion in improving stigma

All monotheistic religions Islam, Christianity and Judaism calls to accept the disease as much as God, satisfaction and calls for tolerance and respect for the patient and good to deal with patients and accept dealing with them in all matters of life. All monotheistic religions call for the patience of the disease and lives with it. This will lead to reduce the stigma of epilepsy. Epileptic seizures have historically been associated with religious beliefs in spirit possession. These attitudes and misconceptions about epilepsy still flourish in developing countries as byproducts of specific sociocultural environments. In Haitian patients with epilepsy whose seizures were initially attributed to Voodoo spirit possession. All patients reported ictal experiential phenomena (epigastric aura, ictal fear, depersonalization and derealization symptoms) followed by complete loss of consciousness. Electroclinical investigations revealed a temporal lobe focus [53].

The perceptions and attitudes associated with epilepsy are different in a Muslim country. Islam, which is the largest religion worldwide after Christianity, contains some interesting elements on its teachings about persons suffering from different types of disorders. One underlying idea is that whatever happens to a person may be the will of God and not necessarily a punishment for something bad they have done [54]. This suggests that persons suffering from disorders should treat with respect and tolerance. Muslims refer to the holy Quran in all aspects of their life, and there are some chapters in the Quran that deal with health and sickness, rules of hygiene, and medical concepts in general. These chapters might make a difference in the public perception of people suffering from epilepsy [55].

Legal and regulatory action

Legislation of perceptions and wrong beliefs is difficult; however, regulations and laws can characterize behavior that may ultimately change attitudes. Information about the Americans with Disabilities Act (ADA) and legal requirements to prove disability is available from the Epilepsy Foundation's website [56] and summarized herein. Courts recognized epilepsy as a disability under state and federal antidiscrimination laws. Successful cases brought under the federal Rehabilitation Act of 1973 recognized

people with seizure disorders as disabled under the law on the basis of the stigma associated with seizure disorders and the varied nature of seizures. Whether epilepsy considered as a disability under the ADA is debatable, however. Congress and the courts, including the Supreme Court, have acknowledged that fear of a person's disability can form the basis for discrimination, and epilepsy is an example of one such disability that can lead to discrimination. However, recent Supreme Court rulings suggest that a person with controlled seizures may not be considered disabled, even if epilepsy-associated stigma limits his or her employment opportunities [57].

Conclusion

For PWE in the worldwide, stigma is one of the most distressing consequences of having seizures, along with the unpredictability of future seizures and the inability to drive. The impact of

stigma on the lives of epilepsy patients is far-reaching, often including effects on interpersonal relationships, general health, employment opportunities, overall quality of life and society. Education about epilepsy directed at the broader community, as well as at the individual with epilepsy, is the most effective means of addressing misperceptions and fear. Education and improved knowledge and attitude against epilepsy are important issues in decreasing stigma of epilepsy.

Ethical Publication Statement

I confirm that I have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Disclosure

I have no conflicts of interest to disclose.

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