

Confronting the stigma of epilepsy

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Abstract

Stigma and resultant psychosocial issues are major hurdles that people with epilepsy confront in their daily life. People with epilepsy, particularly women, living in economically weak countries are often ill equipped to handle the stigma that they experience at multiple levels. This paper offers a systematic review of the research on stigma from sociology and social psychology and details how stigma linked to epilepsy or similar conditions can result in stereotyping, prejudice and discrimination. We also briefly discuss the strategies that are most commonly utilized to mitigate stigma. Neurologists and other health care providers, social workers, support groups and policy makers working with epilepsy need to have a deep understanding of the social and cultural perceptions of epilepsy and the related stigma. It is necessary that societies establish unique determinants of stigma and set up appropriate strategies to mitigate stigma and facilitate the complete inclusion of people with epilepsy as well as mitigating any existing discrimination.

Key Words

Epilepsy, gender issues, quality of life, stigma, treatment gap

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Ann Indian Acad Neurol 2011;14:158-63

Introduction

Epilepsy is one of the most common serious neurological disorders in the world. More than 50 million people worldwide live with epilepsy, and 80% live in economically backward and developing countries.^[1] The estimated prevalence rates for epilepsy suggest that between 6 and 10 million people live with epilepsy in India.^[2] The medical and surgical management of epilepsy has progressed considerably in the recent past. Seizure remission is possible in as many as 70% of patients with appropriate and timely treatment. The advent of advanced diagnostic tools such as the video EEG, magnetic resonance imaging and other ancillary investigations have made it possible to identify specific epilepsy syndromes that respond best to surgery.

Despite these scientific advances, there has been little perceptible progress in the rehabilitation of persons with epilepsy, confirming Wolf's contention that epilepsy exists in two parallel worlds—one of scientific advances in the

management of epilepsy where enormous progress has been witnessed and the other, a darker world of superstition and prejudice that remains quite resistant to the numerous initiatives for people with epilepsy.^[3] Irrespective of the type of epilepsy, this condition continues to have wide-ranging impacts on multiple domains of an individual's life. For instance, a seizure that lasts only a few seconds can result in the complete loss of driving privileges, as Indian law still refuses licenses to people with epilepsy. Epilepsy can influence economic independence through loss of productivity, employment or underemployment due to restrictions on education. Furthermore, people with epilepsy have to contend with the side-effects of medications and the lifestyle restrictions necessary to manage their condition. In addition, people with epilepsy are doubly vulnerable because of the pervasive stigma around the condition in most societies.^[4] Research from USA,^[5] Iran,^[6] Ethiopia,^[7] Zambia,^[8] Vietnam,^[9] China^[10] as well as several European^[11] and Middle Eastern^[12] countries has shown that stigma related to epilepsy is a major concern across the world. Physicians, while often meticulous in their diagnostic and treatment, often fail to address the stigma and consequent psychosocial burden accompanying conditions like epilepsy.

Stigma, as a phenomenon and an analytical framework, is relevant to both the researcher and the clinician for several reasons. First, several studies have demonstrated that illness-related stigma had powerful effects on economic status, psychological wellbeing, social interactions and overall health, even greater than the effects of the illness itself.^[13] Second,

Access this article online	
Quick Response Code:	Website: www.annalsofian.org
	DOI: 10.4103/0972-2327.85873

stigma can interfere with timely access to healthcare, early diagnosis, treatment and adherence to treatment and lifestyle recommendations. A study in Britain that compared epilepsy in people of Indian origin with the native population had shown that fewer people of Indian origin accessed medical care due to greater compulsion to conceal epilepsy; many respondents resorted instead to alternate therapies, particularly when seizures fail to respond to modern medical treatment.^[14] Third, stigma is linked to a broad range of psychosocial consequences, including a loss of self-esteem, social withdrawal and isolation, often influencing others within the social network.^[15] In south India, for instance, parents of children with epilepsy tended to isolate themselves from others in their social network.^[16] Fourth, stigma has the potential to influence the provision of care to people with epilepsy. The negative perceptions of epilepsy among medical professionals and structural discrimination resulting from stigma can impair the service utilization, particularly when there is scarcity of resources for treatment, rehabilitation and research. In order to better understand stigma, this paper presents a systematic overview of the social theories of stigma and draws specific inferences for the medical practitioner who must treat people with epilepsy.

Social Theories of Stigma

The etymological origins of the word “stigma” takes us to ancient Greece, where the term denoted the branding or tattooing practiced on slaves, criminals and those deemed “outside” citizenship and disgraced. Over time, the word has evolved and acquired varying connotations. Today, it has come to represent the underlying disgrace, negative stereotypes, harsh judgments, social disapproval, isolation, ostracism and abjection that are linked to the possession of any “mark” of difference and devaluation. A broad range of characteristics (actual or perceived) have the potential to result in stigma, ranging from tangible “marks” such as leprosy or albinism to more intangible “marks” such as epilepsy or HIV status, in addition to attributes of race, ethnicity, caste, gender, personality, occupation and experience.

One of the first clearest articulations of a theory of stigma came from the sociologist Erving Goffman, who defined stigma as an attribute that has the potential to discredit an individual, and the possession of which results in the “tainting” of social identity.^[17] Those who bear a stigmatizing trait become targets for stereotypes built around that trait, prejudicial attitudes and discriminatory behavior such as shunning, exclusion and punishment. Not all individuals who possess potentially stigmatizing traits are faced with stigma. Stigmatization can be conditional upon the process of “labelling”: individuals with potentially stigmatizing traits are either “discredited” because the attribute is obvious or visible or “discreditable,” which means the attribute is concealed or “secret.” Persons with epilepsy can therefore be perceived as “normal” as long as they do not have public seizures. Once this occurs, the label of epilepsy is assigned; usually by an individual in a position of power—most often this figure is a medical professional. Goffman also pointed out that stigma casts a long shadow that has the potential to impact those who are associated with stigmatized subgroups, including family members and friends.

Further work from social psychology has highlighted that stigma processes are part of the everyday psychological processing, cognitive schema and ordering of the world.^[18] The tendency to stigmatize is considered universal and omnipresent, but this tendency can be altered by conscious thought, changes in social policies, cultural perceptions, individual attitudes and behavior. Social psychologists also explain why different individuals respond to the same stigmatizing trait in different ways. Stigmatization is one among a large and varied set of stressors that individuals must confront. Therefore, the ability to withstand stress imposed by stigma will vary according to the intellectual, psychosocial, social and economic resources available.

Current work on the sociology of stigma extends Goffman’s theories by identifying the processes of stigma.^[19] First, perceivers recognise and identify a trait or difference, which signals that an individual belongs to a particular group. For instance, an observer may see a person having a seizure and label him or her as “epileptic.” Dominant cultural beliefs then link this label to negative stereotypes (such as, an individual with mental illness is considered as dangerous).^[20] Social processes then lead to the separation and isolation of the stigmatized individual, who subsequently experience a loss of social status as well as discrimination (such as unequal health and socioeconomic outcomes). Link and Phelan also underline, rightly, the role of power in the social processes of stigmatization. Social, cultural, economic, political and other forms of power enable stigmatization. Because power relations and norms can vary dramatically across and within societies, this insight is a powerful argument for India-centric research on the social processes and consequences of stigma.

Social Research on Epilepsy-Related Stigma

Focusing primarily on European and North American populations, the works of scholars such as Scambler, Hopkins and Conrad have engaged with the lived experiences of people with epilepsy and resulted in a better understanding of the stigma, particular to epilepsy. Two key concepts that emerged from Scambler and Hopkins distinguished between “enacted” and “felt” stigma.^[21] Enacted stigma refers to acts or instances of discrimination against people with epilepsy on grounds of their perceived unacceptability or inferiority. This could include overt discrimination in the workplace or educational institution, neglect, hostility, abuse or what respondents termed “fair and legitimate” discrimination, such as bans on driving or operating heavy machinery. “Felt stigma” refers to the anticipation or fear of enacted stigma or negative reactions to the disclosure of epilepsy, which also encompasses feelings of “difference” and shame. Felt stigma need not be based on personal experiences of enacted stigma, but is often built upon perceived social responses to epilepsy, and is as debilitating as enacted stigma itself.

The family unit is a necessary component to an understanding of the processes of stigma. Schneider and Conrad suggested that parents may actually (consciously or subconsciously) inculcate stigma in their children by their perceptions, attitudes and actions.^[22] This particular insight is relevant to medical practitioners working with people with epilepsy in India, as the decision to seek treatment is often made in

a family setting and the patient–doctor interaction is also mediated through family members.

Stigma must be understood in relation to routine psychological functioning (for instance, the tendencies to categorize), social processes and groupings as well as structural variables within societies, such as social power, gender roles and social justice. Medical professionals working with people with epilepsy in India cannot treat the condition in a vacuum. She/he must have a good understanding of individual psychological functioning and resources, family dynamics, household power and gender roles in addition to broader social and cultural perceptions of the condition.

Forms of Stigma

This section explores the ways in which stigma related to epilepsy manifests itself among people living with this condition in India, at the individual, familial, social and structural levels. The multiple levels along which stigma can be experienced contribute to the “burden” of epilepsy in ways that cannot necessarily be quantified using traditional measures such as mortality and morbidity measures or the DALY.^[23] At the individual level, stigma can manifest itself in the form of diminished self-confidence, withdrawal, self-imposed isolation, financial losses and tendencies to internalize shame as well as negative perceptions of the self and of epilepsy, all of which have numerous trickle-down effects on practically all aspects of an individual’s life.^[24] At the level of the larger social units, stigma is manifested in multitudinous ways. For instance, epilepsy-related stigma has the potential to influence social variables such as social integration, extent of interaction with social networks and peer group activities.^[25] A young child with epilepsy may be refused continued access to education because social attitudes in educational institutions are prejudicial and discriminatory. In a country where the majority of marriages remain arranged, families of people with epilepsy may confront stigma when they try to arrange marriages. Employers may refuse employment to potential employees with epilepsy, or refuse advancement to existing employees with epilepsy.

Structural stigma can be perceived in the policies of private and state institutions, which systematically discriminate against or restrict the opportunities available to stigmatized groups.^[26] One of the most important of these state institutions is the law—as Burris argued; the law can be a powerful force fighting against the operation of stigma in society and in structuring individual resistance to stigma. Equally, it can play many roles in the assertion or enactment of stigma.^[27] Corrigan *et al.* surveyed state laws in the USA to illustrate the systematic structural discrimination related to mental illness.^[28] Indian legal history provides consistent evidence of structural stigma against people with epilepsy despite avowals in WHO publications that legal constructions of epilepsy in India had evolved.^[29] For instance, the Hindu Marriage Act of 1955 and the Special Marriage Act of 1954 both rendered a marriage null if a partner was subject to “recurrent attacks of insanity and epilepsy.” Several years of legal struggle by the Indian Epilepsy Association resulted in the removal of epilepsy as a criterion for annulment almost at the end of the twentieth century.^[30] A brief overview of the twentieth century judicial records will

reveal that this particular provision was used extensively to discriminate against women with epilepsy, in particular. Even after marriage laws caught up with medical advances and understandings of epilepsy, it remains a contentious issue in family courts across India. The unfortunate but common practice of concealment of epilepsy from spouses is often constructed as fraud and cruelty, and the condition is still offered as spurious evidence that people with epilepsy are incapable of sustaining marital lives.^[31] Recent data from United States had shown that seizures accounted for fatal car accidents less often (0.2%) than drunken driving (31%).^[32] Unlike in the USA and other several countries,^[33] the Motor Vehicles Act in India does not permit issue of license to drive a motor vehicle, if the applicant has epilepsy. Despite the petition to the Indian government by interest groups to legally permit people with epilepsy to drive, there have been little progress on this front. Further, insurance cover to people with epilepsy in India are issued at disadvantageous rates, and are denied benefits in the event of accidents/deaths occurring due to epilepsy.^[30]

The absence of appropriate legal structures that restrict or mitigate discriminatory behavior against people with epilepsy is equally evidence of structural stigma against epilepsy in India. While disability laws in North America and the United Kingdom ensure that employers can ensure that employees with epilepsy do not confront discrimination in the workplace from other employees or regarding access to certain occupations, there are no equivalent legal provisions in India as yet.^[34,35] Therefore, epilepsy in India can still be potential grounds to deny access to employment if the employers, for instance, discover an employee’s or potential employee’s epilepsy and deem that they are unemployable because of their health as the employer is within his/her legal rights to do so. Indian law, as it stands, may perpetuate stigmatization by encouraging people with epilepsy to continue with systematic concealment and secrecy around their conditions, rather than give them the space for disclosure, acceptance, protection and activism.. Structural stigma is also evident through the absence of accurate, flexible legal constructions of epilepsy, which reflect current medical knowledge of the condition. The lack of public spaces accorded to epilepsy is further evidence of the deep underlying structural stigma around epilepsy in India. For instance, there are no national-level awareness programmes to promote accurate perceptions of epilepsy in India. Further, epilepsy is systematically discounted in national public health policies, despite the millions who live with the condition and confront various subsequent challenges.

Measurement and Determinants of Stigma

The measurement or assessment of stigma is a difficult endeavor, as it demands tools that are culturally sensitive yet universally applicable. Instruments that permit quantification include questionnaires (notably knowledge, attitude and reported practice, or KAP surveys) that elicit some information on the existing set of beliefs and perceptions around a particular health condition. One of the commonly used instruments is a three-question screening tool with dichotomous response.^[36] These statements are “I feel some people are uncomfortable with me,” “I feel some people treat me like an inferior person” and “I feel some people would prefer to avoid me.” This was

originally developed for stroke and was subsequently adapted for use in epilepsy. Some researchers have used more elaborate instruments with 10 questions or more.^[37] Scales also permit researchers the ability to calculate the extent of stigma, and changes therein. For instance, work on the US, West Germany, Britain and Italy has all illustrated how negative public perceptions about epilepsy and people with epilepsy have gradually changed over the course of the twentieth century.^[38] Recent developments in the measurement of stigma include the Explanatory Model Interview Catalogue (EMIC), which has been used to assess negative community attitudes, although certain doubts have been raised about its reliability.^[39] However, quantitative approaches have their limits, which can be met by using a combination of quantitative and qualitative tools, which have other advantages. Qualitative methods include informant interviews, focus group discussion and participant observation, all of which permit investigators more detailed understanding of the workings of stigma and prejudice.

The measurement of stigma also allows researchers the opportunity to identify possible determinants. A brief literature review suggests that considerable variation exists in factors associated with stigma. For instance, some studies report a correlation between the length of the period of seizure remission and the levels of stigma.^[40] A European study of the determinants of stigma reported that seizure frequency was positively correlated with stigma in most of the countries in this study.^[41] Nevertheless, other researchers have reported contrarily that stigma or quality of life (QOL) may not necessarily be related to seizure frequency.^[42] Other factors such as gender (Belgium, Portugal, UK), earlier age of onset (France, Germany, Italy, Spain and UK), shorter duration of epilepsy (The Netherlands, Poland and Turkey) and limited knowledge of epilepsy (Germany, Italy, The Netherlands, Poland, Portugal and Turkey) were significantly associated with high stigma.^[41] Persons outside marriage (never married, divorced/separated or widowed) perceived higher stigma than others.^[5] Other variables indicative of higher stigma are socioeconomic, demographic and biomedical. For instance, Dilorio *et al.* concluded that higher felt stigma was correlated with unemployment, limited income, poor control of seizures, greater interference of seizures with everyday activities, lower confidence levels in managing epilepsy, more negative outcomes with seizures and lower patient satisfaction.^[43]

Despite the proliferation of work on the assessment of epilepsy-related stigma in the developed world, there is a paucity of similar systematic research on epilepsy-linked stigma in much of the developing world, and definitely in South Asia. Aside from Aziz's work on Pakistan, there has been research on epilepsy-related stigma in states such as Kerala and Karnataka.^[44] The existing body of work utilised hospital and population-based approaches involving questionnaires, including the KAP, QOL, quality of life in epilepsy surveys and the EMIC. In Mangalore, for instance, Joseph *et al.* found that stigmatization was related to the age and education, of the respondent although unrelated to gender and occupational status.^[45] However, the different roots, manifestations and determinants of epilepsy-related stigma in India are yet to be investigated comprehensively.

Strategies to Mitigate Epilepsy-Related Stigma

One of the most common individual and familial responses to stigma is concealment or partial concealment. In the instance of epilepsy, this means that they conceal all tangible signs of the condition, such as the medication or the seizures themselves, as much as possible. Persons with epilepsy avoid or try to limit stigmatization by managing information through two processes: either general concealment or selective or preemptive disclosure.^[46] However, concealment as a stigma management strategy has its disadvantages and has been known to contribute to increased expectations of rejection and stigmatization, often resulting in a vicious cycle of secrecy, withdrawal, isolation and socially maladaptive behaviors.^[47]

In recent years, the World Health Organization, the International Bureau of Epilepsy and the International League against Epilepsy have emerged with a global campaign against epilepsy called "Out of the Shadows." One of the major themes of this initiative was to reduce the stigma around this condition, and programmes including demonstration projects in China, Brazil and other countries have attempted to achieve stigma mitigation. The demonstration project in China had identified a persistent and considerable knowledge gap in rural China regarding almost all aspects of epilepsy. Here, people turn to traditional Chinese practitioners as much as practitioners of modern medicines. The Chinese researchers also suggest that effective community education programs about epilepsy must include the joint training and education of practitioners of traditional and modern medicine.^[48] The Brazilian survey adopted a multipronged approach to stigma and education and training was provided to healthcare professionals and school teachers. In addition, the project came up with a stigma assessment tool, which revealed how stigma was heterogeneous, dynamic and contingent upon social, linguistic and cultural factors.^[49] Similar projects on the scale attempted in China and Brazil, however, have yet to be undertaken in India.

Conclusions

This paper provides a review of the major social theories of stigma and uses these theories to chart out the different forms of stigma experienced by Indians with epilepsy. This theory also suggests that the contextual nature of stigma necessitates country, and even region-specific or language-based initiatives, which take into consideration local economic conditions, cultural constructions of epilepsy, indigenous medical practices, vulnerable social subgroups, social mores, gender roles and power dynamics within the society. The work of the social psychologists can further inform initiatives against epilepsy-conscious efforts that augment and support the social, economic, political, intellectual and financial resources of people with epilepsy are likely to best equip them to cope with stigma.

What initiatives are formulated in India must move beyond public information programmes, which, while being known to enhance self-esteem in people with epilepsy, are hardly sufficient in a country where epilepsy is not yet on the state's public health radar.^[50] A more comprehensive approach must include interventions at the levels of the individual, the family,

the care system (i.e., adequate training must be provided to caregivers in the medical system) as well as in public spheres such as the state and the media. Medical professionals must be aware of the domino effect of a diagnosis of epilepsy and take the time to discuss with patients and their families the possible psychosocial consequences and how they may be addressed. Doctors should be on the watch for any misconceptions and misunderstandings about epilepsy and ensure that all members of the family are fully aware of the condition through accurate information. It is important that each society sets up its own studies to quantify the stigma, characterize its determinants and then attempt to develop strategies to mitigate it.

In addition, we call for systematic and comprehensive research that examines the origins and implications of stigma, how prejudicial beliefs are generated and perpetuated and how and when they translate into discriminatory behaviors. How stigma impairs access to healthcare and medical treatment must be another locus of research. Further, research on epilepsy-related stigma needs to be able to calculate the cost of epilepsy-related stigma to individuals, families and larger entities such as the community and the state itself.^[51] Equally relevant is the need to frame these analyses of epilepsy-related stigma in the Indian subcontinent within the discourses on gender and power. We must be able to identify vulnerable subgroups within the population, whose susceptibility to stigma is higher. A greater understanding of the ways in which epilepsy-related stigma has contributed to the apathy of state actors toward improving provisions for individuals with epilepsy is also necessary. These steps would reduce the treatment gap, bring more persons with epilepsy into remission and improve their QOL, as has already been proven through research in other parts of the world.

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How to cite this article: Thomas SV, Nair A. Confronting the stigma of epilepsy. *Ann Indian Acad Neurol* 2011;14:158-63.

Received: 28-04-11, **Revised:** 17-05-11, **Accepted:** 08-09-11

Source of Support: Nil, **Conflict of Interest:** Nil

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