

---

## Impact of Social Stigma on Life of Epilepsy Patient-A Literature Review

Mr.Vipin Vageriya

HOD of Child Health Nursing, Manikaka Topawala Institute of Nursing –CHARUSAT, Changa, Ta. Petlad, Dist. – Anand, Gujarat

---

**Abstract:** Epilepsy is a disorder in which nerve cell activity in the brain is disturbed, causing seizures. It affects social, physical, mental wellness of person suffer with epilepsy. Social stigma affects very deeply to the epileptic patient.

**Methods-** A systematic literature review is planned to find out the impact of stigma on epileptic person's life.

**Electronic search to Collect Literature--**The following electronic databases are searched: ProQuest, Embase, Pubmed, EBSCO, Scopus, the British Nursing Index and the Cumulative Index to Nursing & Allied Health Literature (CINHAL) and journal available in library.

**Result--** Stigma and resultant psychosocial issues are major hurdles that people with epilepsy confront in their daily life. It is necessary that societies establish unique determinants of stigma and set up appropriate strategies to mitigate stigma and facilitate proper support to epileptic client.

**Conclusion:** Proper guideline and awareness camp has to organize to avoid the stigma regarding epilepsy tendency.

**Keywords:** Epilepsy, Stigma, Social impact, Burden.

### 1. INTRODUCTION

Epilepsy is a major public health problem across the world, not only because of the problem that arises as a result of seizure activities, but also due to the social & cultural stigma attached to it. It has a serious implication for the individual and the family in various life domains, usually more serious than those of other chronic diseases. The problems that persons with epilepsy go through vary from interpersonal & emotional adjustment, family coping and adjustment within marital relationship, issues surrounding children, employment, economic burden & stigma about the disease and treatment that exist in the society. Epilepsy can affect the lives of other family members besides the persons. The caregivers of persons with Epilepsy undergo severe emotional, physical, economic burden due to the nature, chronicity, disability and stigma attached to the illness.

Epilepsy is a major public health concern in terms of the burden of the disease, nature of illness and its impact on individuals and families.

The International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) define epilepsy as a brain disorder characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological and social consequences of this condition.<sup>1</sup>

### 2. SEARCH STRATEGY AND SELECTION CRITERIA

The initial online search retrieved 746 records. After exclusion, only 43 full text articles are available. Previous review papers on epilepsy were examined carefully for relevant references.

**Methods of Collecting Literature--**The following electronic databases are searched: ProQuest, Embase, Pubmed, EBSCO, Scopus, the British Nursing Index and the Cumulative Index to Nursing & Allied Health Literature (CINHAL) and journal available in library.

### 3. LITERATURE

Epileptic patients are often neglected in our society. Hospital based cross sectional study was done among epileptic patients in Mangalore city of south India in February 2011. Epileptic patients aged 7 or more were interviewed

---

using a pretested semi-structured questionnaire. Standardized scales were used for assessing the quality of life (QOL), stigma and self-management practices of patients. Association of these parameters was done with various socio demographic factors of patients. Of the 56 patients, 55.4% patients had GTCS and 80.4% had multiple episodes of seizures. QOL and self management practices were good in 44.6% and 71.4% patients, respectively. Self-management practices was found to significantly improve with age of patients ( $P=0.012$ ). Educational status of patients was found to significantly improve their QOL and self-management practices ( $P=0.031$ ). Stigmatization was reported by 66.1% patients and it was significantly more in patients in the age groups 30 to 50 years ( $P=0.043$ ). Gender and occupation of patients was not significantly associated with any of the parameters. Self-management practices were good in most patients but this was not so with QOL or experience of stigma. These aspects could be improved by educating the people in order to generate greater social support for epileptic patients in future.<sup>2</sup>

Epilepsy is a common neurological disorder whose consequences are influenced socially and culturally, especially in India. This review (second of the two part series) was carried out to understand the social impact and economic burden to develop comprehensive program for control and prevention of epilepsy. Epilepsy is known to have adverse effect on education, employment, marriage, and other essential social opportunities. Economic burden associated with epilepsy is very high with treatment and travel costs emerging as an important contributing factor. A vicious cycle between economic burden and poor disease outcome is clear. There is no significant change in the perception, stigma, and discrimination of epilepsy across the country despite improvement in educational and social parameters over the time. The huge treatment gap and poor quality of life is further worsened by the associated co morbidities and conditions. Thus, a multidisciplinary response is needed to address the burden and impact of epilepsy which calls for an integrated and multipronged approach for epilepsy care, prevention, and rehabilitation. Service delivery, capacity building, integration into the existing program, mobilizing public support, and increasing public awareness will be the hallmarks of such an integrated approach in a public health model.<sup>3</sup>

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.<sup>4</sup>

For many people with epilepsy, the continuing social reality of their condition is as a stigma. Epilepsy stigma has three different levels; internalized, interpersonal, and institutional. While there have been documented improvements in public attitudes towards epilepsy, the remnants of "old" ideas about epilepsy continue to inform popular concepts resulting in a difficult social environment for those affected. The social and quality of life problems arising from a diagnosis of epilepsy can represent greater challenges than are warranted by its clinical severity. The relationship between stigma and impaired quality of life is well documented. Tackling the problem of stigma effectively requires that all three of different levels at which it operates are systematically addressed.<sup>5</sup>

People With Epilepsy (PWE) and their families often face a very common aspect of this neurological disease epilepsy, known as Epilepsy Stigma (ES). ES is considered to be one of the most important factors that have a negative influence on PWE. It is a commonly encountered global issue among PWE in all cultures. ES may have deleterious effect on the patient's life more than the disease of epilepsy itself. It is the prime duty of all health professionals to try and manage ES in order to improve the quality of life of PWE not only by controlling the seizures, but also by fighting the myths and disbelief of stigma and managing the disease with a better approach. Stigma in PWE can be encountered and dealt with by diverse specialties in health profession including physicians, surgeons, social workers, psychologists, psychiatrists and nurses. Unfortunately this important issue of ES is addressed primarily in specialized journals like Epilepsy Research, Epilepsia, Epilepsy and Behavior, Seizure and Social Science Medicine which are read by professionals interested mainly in epileptology or social sciences,

whereas the actual problem of ES and its management remains neglected and does not reach the common readers and the non-scientific communities which form a major part of the society in any culture or country. Thus, there is an obvious need that this issue should be addressed in simple language in journals targeting readers of different specialties and interests through publishing articles on ES in popular magazines and dailies of the local areas globally.<sup>6</sup>

Stigma is a major issue for people who develop epilepsy. Reducing stigma is a major focus of activity for the epilepsy patient support groups globally. In this paper, we introduce some key ideas and debates about the nature of and drivers for the stigma of epilepsy, including recent arguments about the need to frame analyses of the nature of epilepsy stigma within sociological debates about conflict and power. We then consider the role of the legislative process for redressing power imbalances that promote or maintain epilepsy stigma; and the value of tailored educational campaigns and programmes directed at stigma reduction. Finally, we consider the nature of 'difference' as experienced by people with epilepsy and how that difference translates into stigma; and provide evidence from a specific targeted intervention to combat epilepsy stigma that its reduction is an achievable goal.<sup>7</sup>

Epilepsy stigma is a social determinant of ill health that affects the quality of life of people who suffer from epilepsy and that render a poor social prognosis even worse than the clinical one. From a phenomenological approach, between January and July 2011, we explored the experience of epilepsy stigma through 25 in-depth qualitative interviews with 10 persons with temporal lobe epilepsy (PWE) (we avoided terms such as "epileptics" or "epileptic patients" because they can be labeling and stigmatizing), 10 carers (CEs) of PWE who attended the epilepsy clinic of the Institute of Neurology and Neurosurgery of Mexico, and 5 physicians specialized in epilepsy. The objective of the study was to identify the following: perceptions that could indicate any form of discrimination due to having epilepsy, reactions of people in front of a person having seizures, and social functioning of PWE since epilepsy onset, particularly their interpersonal relationships and participation in educational or working activities. Through the health providers' narratives, we explored the mainstream care practices, their perspectives on epilepsy, and their views about how the disease should be addressed. Thematic guidelines were elaborated for each type of participant. All information was processed with the use of the computer-assisted data analysis, Atlas.ti5. We made a codification of broad themes that corresponded to the main topics of the interview guidelines and then proceeded to finer categorization to elaborate the analytical categories. Epilepsy was attached to a powerful stereotype that includes notions of contamination, danger, sin, divine punishment, supernatural forces, and madness. Internalized, interpersonal, and institutional stigma prevents PWE from participating in school and employment and reduces their opportunities to establish peer and couple relationships. Mexican's overt impunity of structural discrimination towards PWE shows a lack of available legal resources that protect their human rights. The narrow biomedical concept that physicians have of epilepsy is consistent with the limited medical practices that are offered to treat epilepsy at the health services in Mexico. Comprehensive treatment and integrated services for epilepsy must incorporate psychosocial programs that include epilepsy stigma as a major component of the disease.<sup>8</sup>

**Result**—Over all, it is noted that stigma especially in developing country directly affect the behavior and social life of epileptic person. Stigma and resultant psychosocial issues are major hurdles that people with epilepsy confront in their daily life. It is necessary that societies establish unique determinants of stigma and set up appropriate strategies to mitigate stigma and facilitate proper support to epileptic client.

#### **4. CONCLUSION**

The relationship between stigma and impaired quality of life is well documented. Tackling the problem of stigma effectively requires that all three of different levels at which it operates are systematically addressed

#### **REFERENCES**

- [1] Fisher RS, van Emde Boas W, Blume W, Elger C, Genton P, Lee P, *et al.* Epileptic seizures and epilepsy: Definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia* 2005;**46**:470–2.
- [2] Nitin Joseph\*, Ananya Ray et al " Assessment of quality of life, stigma associated and self-management practices among patients suffering from epileptic seizures: A cross sectional study" *Journal of Neuroscience and Behavioural Health* Vol. 3(7), pp. 91-98, July 2011

- [3] Amudhan S, Gururaj G, Satishchandra P. Epilepsy in India II: Impact, burden, and need for a multisectoral public health response. *Ann Indian Acad Neurol* 2015;18:369-81
- [4] Thomas SV, Nair A. Confronting the stigma of epilepsy. *Annals of Indian Academy of Neurology*. 2011;14(3):158-163. doi:10.4103/0972-2327.85873.
- [5] Jacoby, A. and Austin, J. K. (2007), Social stigma for adults and children with epilepsy. *Epilepsia*, 48: 6–9. doi:10.1111/j.1528-1167.2007.01391.x
- [6] M. Ahmad , 2011. Epilepsy: Stigma and Management. *Current Research in Neuroscience*, 1: 1-14.
- [7] Paula T. Fernandes a , Dee A. Snape b , Roy G. Beran c , Ann Jacoby d , \* “Epilepsy stigma: What do we know and where next?” *Epilepsy & Behavior* 22 (2011) 55–62
- [8] Mariana Espínola-Nadurille, Daniel Crail-Melendez et al “Stigma experience of people with epilepsy in Mexico and views of health care providers” *Epilepsy & Behavior* , March-2014Volume 32 , 162 - 169