

Inverse relationship between stigma and quality of life in India: Is epilepsy a disabling neurological condition?



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ABSTRACT

Objective: Stigma associated with epilepsy has negative effects on psychosocial outcomes, affecting quality of life (QOL) and increasing disease burden in persons with epilepsy (PWEs). The aim of our study was to measure the impact of stigma on the QOL of PWEs and the prevalence of neurological disability due to stigmatized epilepsy.

Method: A prospective observational study with a sample of 208 PWEs was conducted. Neuropsychological Tests used were the Indian Disability Evaluation Assessment Scale (IDEAS) to measure disability, the Dysfunctional Analysis Questionnaire (DAQ) to measure QOL, and the Stigma Scale for Epilepsy (SSE) to assess stigma.

Results: Spearman correlation was calculated, and stigma (SSE) was highly significant with QOL (DAQ) (0.019) and disability due to stigmatized epilepsy (IDEAS) (0.011).

Conclusion: The present study supports the global perception of stigma associated with epilepsy and its negative impact on their overall QOL and its contribution to the escalation of the disease burden.

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1. Introduction

1.1. The impact of epilepsy

Epilepsy is a disorder which affects the individual's overall well-being [1,2], and impacts QOL [3]. Neuropsychologically, it leads to many cognitive deficits, most prominently, memory deficits in temporal lobe epilepsy, including working memory [4] and executive functions [5]. Memory dysfunction has a strong correlation with lower scores on measures of QOL [6].

Emotionally, it causes fear of seizures, anxiety, depression, family conflict, and struggles with independence. Persons with epilepsy have a higher incidence of depression than the general population [7], and suicide rates are also high in PWEs [8,9].

Socially and economically, it has significant health-care need implications. An Indian study revealed the total cost per epilepsy case being US\$ 344/year (estimated as 5 million cases) equivalent to 0.5% of gross national product [10]. Discrimination and social stigma surround epilepsy worldwide, which is often more difficult to overcome than the seizures themselves [10]; hence, PWEs are subjected to prejudice.

Therefore, epilepsy affects physical, neuropsychological, emotional, social, and economic domains, creating a vicious cycle of epilepsy, stigma, and disability (Fig. 1: E–S–D Model).

1.2. Relationship between stigma and QOL of PWEs

Stigma has been considered to be an important factor in epilepsy, leaving a negative influence on the PWEs and their family [11–13].

At the individual level, stigma can manifest in psychosocial form involving all aspects of an individual's life [14]. Socially, stigmatized epilepsy has the potential to influence social integration, extent of interaction within social networks, and peer group activities [15]. Hence, society/community is afraid of working with PWEs, thereby affecting their psychosocial domains/QOL [16] (Fig. 1). In India, 90% of PWEs are not treated, and 50% of them do not have access to drugs. Stigma hinders the Indian population from truly understanding epilepsy and affects treatment-seeking behavior. Further, the physical manifestation of seizures that are characteristic of epilepsy may seem scary to people with limited knowledge about epilepsy and contribute to this social stigma [17].

1.3. Epilepsy: hidden epidemic of disability

Epilepsy has contributed to more than 7 million disability adjusted life year (DALY) losses and 0.5% of the global burden of disease in

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Supporting Figure 1: A Vicious Cycle Of Epilepsy-stigma-Disability (E-S-D) Model

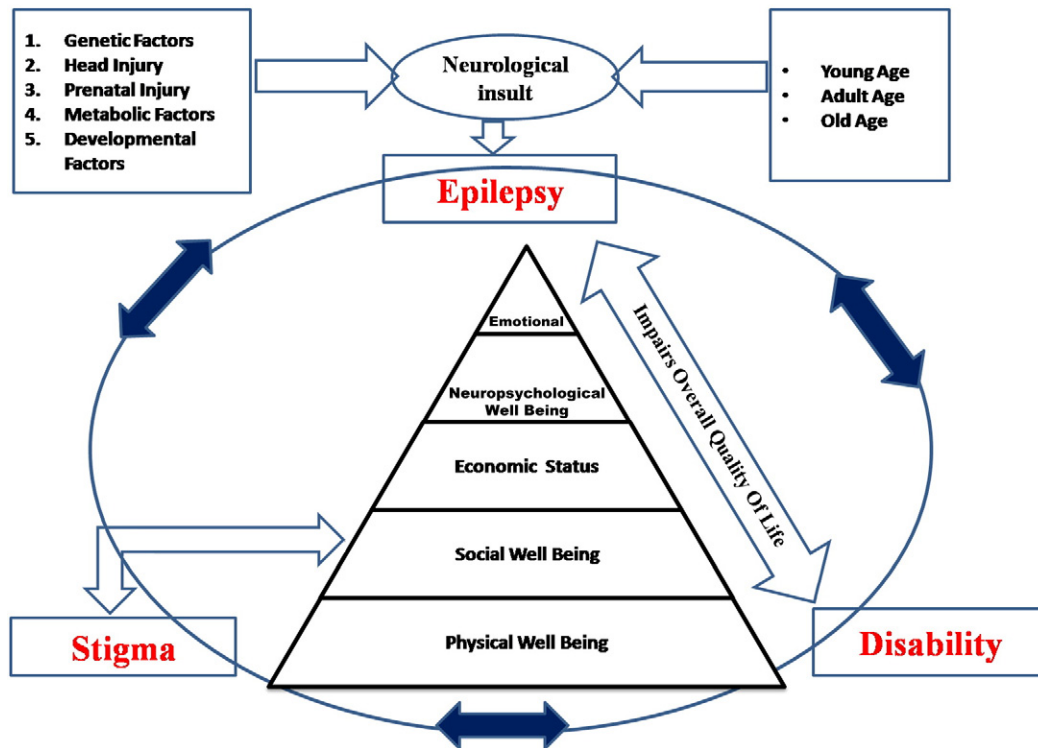


Fig. 1. A Vicious Cycle Of Epilepsy-stigma-Disability (E-S-D) Model.

2000 [18,19]. This includes “disability” and “mortality” in the evaluation of the burden of disease. The disability in epilepsy is often subtle and is frequently overlooked and undervalued. It is apparent that close to 90% of the worldwide burden of epilepsy is to be found in developing regions, with more than half occurring in the 39% of the global population living in countries with the highest levels of premature mortality and lowest levels of income [20].

Considering the global burden, developed countries have various laws to protect the rights of PWEs. For example, the USA has equal employment opportunity commission, family law for parents with epilepsy, etc. [21]. Germany has a disability grading based on seizure frequency and severity. Mild forms of seizures constitute 50–60% disability, more frequent seizures without loss of consciousness constitute 60–80% disability, and frequent seizures constitute 90–100% disability, with privileges offered to PWEs [22].

In India, discrimination is extremely pronounced in socialization, marriage, employment, driving, and disability rights; hence, equal rights are a tough goal to achieve and remain elusive. For example, Indian marriage could only be solemnized if neither party suffered from epilepsy. However, with immense herculean effort, an amendment to this was enacted in 1999 [23]. There is also no provision of special driving licenses to PWEs, no matter how long they have been seizure-free.

Epilepsy is not included in the ‘disability’ category [24], thereby making it a hidden epidemic in India. Only recently, neurological disability has been included in the draft bill of Rights of Persons with Disabilities [25], thereby maintaining the law of equality and reducing the stigmatization and discrimination, but this has not been studied or implemented for epilepsy.

Therefore, we proposed the Epilepsy–Stigma–Disability (E–S–D) Model, which demonstrates how epilepsy is overshadowed by stigma and hampers the neuropsychological, economic, social, physical, and emotional well-being of the individual leading to impaired quality of life (Fig. 1). Its origin is based on epilepsy being a highly hidden and stigmatized entity in our community; this is based on managing a large PWEs. India has more than 10 million PWEs who are impacted

by epilepsy stigma be it in school education, vocation, marriage, or social life. Hence, it was our hypothesis that studying stigma in epilepsy will help in the identification of the role it plays in causing disability and help evolve strategies to reduce its impact on psychosocial domains [26].

1.4. Objective

This study aimed to measure the impact of stigma on the QOL of PWEs and the prevalence of neurological disability due to stigmatized epilepsy.

2. Materials and methods

2.1. Methodology

This was a prospective observational study to estimate the likelihood of impact of stigma on the QOL of PWEs and to evaluate the prevalence of neurological disability due to stigmatized epilepsy. In our tertiary care center with cost-free services, a nonprobability sampling was used, in which all consecutive samples were enrolled which consisted of 208 subjects (males: $n = 73$ and females: $n = 135$; between the age range of 4 to 54 years), who had active epilepsy (history of seizures for at least 6 months as per the ILAE 1989 classification system) [27]. These PWEs were recruited from the epilepsy clinic of the Neurology Department at AIIMS, New Delhi, from January 2010 to June 2011. Apart from this, a complete detailed history was taken, which included clinical seizure characteristics, treatment details, and associated comorbidities. A medley of standardized clinical questionnaires was applied to assess these patients for stigma and disability and its effect on their quality of life (Supporting Fig. S2). The applied questionnaires were categorized into two areas: one refers to neuropsychological tools, and the other refers to social tools. The diagrammatic representation of the study design is given in Fig. 2.

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