

# Outcomes of Perceived Stigma Among Epilepsy Patients

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## ABSTRACT

**Objective:** The purpose of present study was to study the impact of perceived stigma on three outcomes including self-concept, self-esteem and social isolation among people with epilepsy. **Study Design:** Purposive sampling technique. **Duration:** October 2014 to May 2015. **Setting:** Awan Clinic Sargodha, CDA Hospital Islamabad and Col. Masood's Psychiatric Clinic, Lahore. **Methodology:** The sample consisted of 186 people with epilepsy. To collect the data The Stigma Scale, Six Factor Self-concept Scale, Rosenberg Self Esteem Scale and Social Network Index were used to measure the variables under study. **Results:** Results showed that perceived stigma had considerable negative connection with self-esteem and social isolation, moreover minor connection with self-concept was noticed. Regression analysis revealed that stigma is a very important negative predictor of self-esteem and social isolation. **Conclusions:** The present study was an attempt to highlight the psycho-social issues which play an important role in the lives of epileptic patients. It can assist clinical psychologists and psychiatrists to understand clearly the strong impacts of stigma to bring awareness among masses.

**Keywords:** Epilepsy, Perceived Stigma, Self-concept, Self-esteem, Social Isolation.

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## INTRODUCTION

Epilepsy is both a medical diagnosis and a social label. People with epilepsy have been stigmatized and discriminated against for long times, being treated as insane, evil, and possessed of evil spirits or contagious<sup>1</sup>. The history of epilepsy can be précised as 4000 years of ignorance, superstition and stigma, followed by 100 years of knowledge, superstition and stigma. Even in modern societies, they have been institutionalized, segregated and socially rejected<sup>2</sup>. Due to this stigmatization and discrimination, people with epilepsy have been the target of prejudicial behavior in many spheres of life, over many centuries and in many cultures<sup>3</sup>. At present several people are facing this stigmatization and due to this social label multiple psychological, psychiatric and social problems are getting common in the epileptics<sup>4</sup>. These may include reduced quality of life, poor self-esteem and social anxiety<sup>5</sup>. Some of the psycho-social problems (i.e. self-concept, self-esteem and social isolation) and the stigma related to them are studied in the present research.

The word stigma is also believed as a tattoo or brand and originated from Greek word stizein, a cut into the flesh or a distinguishing mark burned of criminals or slaves by Ancient Greeks so that the other people would know who these individuals were; and that they were the members of society which were not valued. Though the term stigma was not used by Greeks relative to psychological disease but the stigmatizing approaches of the people about the ailments were previously clear with the logic that the mental sickness was linked with thought of humiliation, embarrassment and loss of expression<sup>6</sup>.

At present, despite the modernization of the societies, there are still false ideas and concepts about people with epilepsy which results in difficult social environment for the epilepsy patients<sup>6</sup>. According to few studies people with epilepsy who don't have much knowledge about epilepsy have poor self-concept as compare to those who got knowledge about their disease. Due to lack of awareness about the disease, stigma of epilepsy has negative effects on the self-concept and self-esteem of epileptic patients particularly in developing countries<sup>6</sup>. A person's self-concept is the idiosyncratic collection of attitudes and beliefs about him or herself. It embraces thoughts and feelings about one's weaknesses, abilities, strengths and limitations<sup>7</sup>. Research explained that youngsters having epilepsy report lower level of self-respect. A recent study in India has been conducted to check the relationship between felt stigma and self-esteem and found significant results<sup>10</sup>.

A constructive self-esteem is a human requirement, necessary to well adjustment, and appreciably linked with personal approval and perfect functionality<sup>10</sup>. Because of the long-term treatment through medication and the stigmatization linked with the label of epilepsy, it is considered a very disturbing or distressing disease which definitely have strong effect on the self-esteem of the individual. In short, self-esteem is an individual decision of value that is uttered in the position the person holds toward himself<sup>7</sup>. Individuals with epilepsy report adverse level of self-esteem as compared to the people without epilepsy<sup>8</sup>.

Individuals with epilepsy can experience social isolation influencing relationships, whether with family or friends. Social isolation can be a consequence of the symptoms of numerous

mental health troubles as well as a consequence of the related stigma that person with mental illness can face. Researches revealed that the variables independently related with feelings of stigma were experience of marital issues, experience of social isolation, and presence of anxiety disorder<sup>9</sup>. In south India, parents of children with epilepsy tended to isolate themselves from others in their social network<sup>11</sup>.

There are over 50 million sufferers of epilepsy in the world, 85 per cent of whom live in developing countries. The crude prevalence rate of epilepsy in Pakistan was 9.98 in 1,000 (14.8 in 1,000 in rural and 7.4 in 1,000 in urban areas)<sup>10</sup> which encourage the researchers to focus on this topic. The existing literature suggests that in Pakistan, the studies on epilepsy have more focus on the prevalence<sup>11</sup> and causes of epilepsy<sup>10</sup>. This particular study was also an attempt to gain knowledge about the different psycho-social problems and the impact of stigma in the epileptic patients. The study examined the effect of perceived stigma on three outcomes including self-concept, self-esteem and social isolation among epilepsy patients. The study hypothesized that perceived stigma will negatively predict self-concept, self-esteem and positively predict social isolation among epilepsy patients.

## METHODOLOGY

**Study Design:** Purposive sampling technique.

**Place of Study:** Awan Clinic Sargodha, CDA Hospital Islamabad and Col. Masood's Psychiatric Clinic, Lahore.

**Duration of Study:** October 2014 to May 2015.

## RESULTS

Table 1 shows means, standard deviations and alpha reliabilities of the scales used in the present study which are ranging from .54 to .86. Pearson correlations between the study variables are also shown in Table 1.

Table 1: Psychometric properties and Pearson correlation among variables

Variable								Range		Skewness
	1	2	3	4	M	SD	$\alpha$	Potential	Actual	
1. Perceived stigma	-	-.00	-.27***	.45**	91.55	15.41	.86	0-4	53-129	.33
2. Self-concept		-	-.04	.15*	141.12	25.60	.87	1-7	54-215	.11
3. Self-esteem			-	.24***	19.41	3.11	.54	0-3	11-26	-.48
4. Social isolation				-	23.59	4.07	.70	0-4	14-40	.60

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

Table 2 shows that Stigma is a significant predictor of RSES at [ $F(1, 184) = 14.81, p < .001$ ] and explains 6.9 % variance that could be attributed to Stigma. However, non-significant results were found between perceived stigma and social isolation.

Table 2: Linear Regression showing effect of perceived stigma on self-esteem and social isolation

Variables	Self-esteem		Social Isolation	
	$\Delta R^2$	$\beta$	$\Delta R^2$	B
Perceived stigma	.069	-.273***	.004	.044

\*\*\*  $p < .001$ .

## DISCUSSION

At present twenty-five percent of adults having epilepsy describe social stigma as a result of their epilepsy. The social

## Methods:

Co-relational research method was used to conduct the present study. Sample from epilepsy patients ( $N = 186$ ) was selected through purposive sampling technique. Both males ( $n = 107$ ) and females ( $n = 79$ ) were added in the sample.

Stigma Scale was used to measure the perception of stigma among epilepsy patients. The scale is a 28-item self-report questionnaire. It is a five-point Likert type scale. Nine items were reversely coded in the scale. The internal consistency of stigma scale was .87. Cronbach's alpha for the subscale discrimination was .87, for disclosure .85 and for the positive aspects .64<sup>12</sup>. Six Factor Self-concept Scale was utilized to measure the self-concept of epilepsy patients. The scale consists of 36 items. It is 7 point Likert type scale<sup>13</sup>. Rosenberg Self Esteem Scale was used to measure self-esteem of epilepsy patients. The scale consists of 10 items and do not have any subscales. It is a four-point Likert type scale in which five items are reversely coded. The alpha for various samples ranged from .77 to .88<sup>14</sup>. Social Network Index was used to measure level of social isolation among epilepsy patients. The scale is an 11-item self-report scale with 5 point-rating scale. Alpha for the scale was .64<sup>15</sup>.

The patients with diagnosed epilepsy and who were able to read and write, were only included in the sample. First, consent was ensured from concerned authorities and from the participants and then scales were administered on them. They were also provided with the instructions required to fill the questionnaire. The received data was analyzed using SPSS version 20 and regression analysis was applied for the hypothesis testing.

label "epileptic" is thus considered a major cause of the "psychosocial" problems of people with epilepsy<sup>16</sup>. The findings of the present study were in line with the previous studies as the

study hypothesized that perceived stigma and social isolation are significantly correlated with each other which was accepted. These results were in line with the previous studies such as a study found that stigma is related to a broad variety of psychosocial consequences, counting a loss of self-esteem, social isolation and withdrawal and it also influences others within the social network<sup>17</sup>. An Australian study informed that two-thirds of citizens affected by a mental illness suffer loneliness “frequently” or “all of the time”. The study says in comparison, just 10 per cent of the common populace reported sense of loneliness<sup>18</sup>.

Few results were contrary to the expectations of the present study, as the second hypothesis stated that there will be significant relationship between perceived stigma and self-concept but the correlation analysis found non-significant relationship between the perception of stigma and the self-concept. Some previous studies also found similar results i.e. there were non-significant dissimilarities in total self-concept among normative control subjects and AWE<sup>19</sup>. According to Finlay despite the strong belief in the perception of stigma to have impact on the self-concept of an individual, there is little evidence in favor of the idea that stigmatized individuals have low self-concept<sup>20</sup>. Several studies with a wide range stigmatized groups showed that people either had equal level of self-concept or higher than, non-stigmatized groups<sup>21</sup>.

Some possible reasons for current findings could be the practices of techniques which tend to protect self-concept, for instance the use of discerning social contrasts or provenances of predisposition to the higher status group.<sup>22</sup> Jones and his subordinate’s highlights that self-concepts depend on the details, which is selected as indicative and vital for the self as people cannot respond to all the details that might be authentic.<sup>23</sup> For some people the stigma will be important to the self. For instance, overweight and low self-esteem women tend to project negative feelings and attitude towards overweight people. This association was found to be non-significant for overweight men. It was also observed that overweighed man is less vulnerable to low self-concept as compared to overweight women.<sup>24</sup>

Further justification for the results can be settings in which a person with epilepsy is living. If there are other people in the surroundings, living with similar stigma then it will decrease the salience of the stigma and people will focus on other characteristics of other people. In such settings, the more extreme forms of the stigma are more likely to get attention and lesser forms regress into the background. A study worked on deaf population and suggested that increasing interactions with other deaf people is a coping mechanism which can improve self-concept through avoidance of awkward mixed interactions<sup>25</sup>.

The present study also hypothesized that significant negative correlation exists among perceived stigma and self-esteem which was also accepted. The results are according to the expectations as the previous literature also suggested similar findings. Westbrook and his colleagues worked on a theoretical structure and tried to describe the relationship of stigma to self-

esteem amid adolescents with epilepsy. The study hypotheses were to find relationship amongst several features of epilepsy (seizure frequency, seizure type, and interval of epilepsy), self-esteem, management of disclosure, and perceived stigma. Results of the study found that (a) Seizure frequency and seizure type estimated low self-esteem, and (b) the conviction that epilepsy is stigmatizing estimated low self-esteem<sup>15</sup>.

## CONCLUSION





Findings of the study revealed that perceived stigma negatively affect the self-concept and self-esteem of epilepsy patients whereas perceived stigma do not have any significant influence on social isolation. In Pakistan, the focus is more on the medical issues related to epilepsy like prevalence, causes and treatment of the disease whereas the psycho-social issues related to epilepsy also play vital role in the lives of epilepsy patients. The results can guide the clinical psychologists and psychiatrists towards better understanding of different psycho-social problems faced by the epilepsy patients.

## REFERENCES

1. Hills M. Overcoming the stigma of epilepsy. *Neurol Asia*. 2012;15(1): 21-4.
2. Pahl K, de-Boer HM. Epilepsy and rights. In: Atlas: epilepsy care in the world. Geneva: World Health Organization. 2005.
3. Heersink M, Kocovski NL, MacKenzie MB, Denomme K, Macrodimitris S. Social Anxiety and its Psychosocial Impact on the Lives of people with Epilepsy. *Epilepsy Behav*. 2015;51:286-93.
4. Lee, SA. What we confront with employment of people with epilepsy in Korea. *Epilepsia*. 2005;46(1):57-8.
5. Hirfanoglu T, Serdaroglu A, Cansu A, Soysal AS, Derle E, Gucuyener K. Do knowledge of, perception of, and attitudes toward epilepsy affect the quality of life of Turkish children with epilepsy and their parents? *Epilepsy Behav*. 2009;14(1):71-7.
6. Turki M, Bouchhima I, Halouani N, Turki E, Bouzidi N, Dammaka M, Amami O, Mhiri C. Epilepsy and Self-esteem. *European Psychiatry*. 2016;33:384-5.
7. Ekinci O, Isik U, Gunes S, Yildirim C, Killi Y, Guler G. Self-concept in Children and Adolescents with Epilepsy: The Role of Family Functioning, mothers’ emotional symptoms and ADHD. *Brain Dev*. 2016;38(8):714-22.
8. Kumari S, Banerjee I, Majhi G, Chaudhary S, Singh AR, Verma AN. Felt Stigma and self-esteem among psychiatric hospital outdoor and community camp attending patients. *Med J DY Patil Univ*. 2014;7(5):550-7.
9. Scatolini FL, Zanni KP, Pfeifer IL. The Influence of Epilepsy on Children’s Perception of Self-concept. *Epilepsy Behav*. 2017;69:75-9.
10. Yeni K, Tulek Z, Bebek N. Factors Associated with Perceived Stigma among Patients with Epilepsy in Turkey. *Epilepsy Behav*. 2016;60:142-8.
11. Westbrook LE, Bauman LJ, Shinner S. Applying stigma theory to epilepsy: a test of a conceptual model. *J Pediatr Psychol*. 1992;17(5):633-49.
12. Bielen I, Freidrich L, Sruk A, Prvan MP, Hajnsek S, Petelin Z, Susak R, Candric M, Jacoby A. Factors Associated with Perceived Stigma of Epilepsy in Croatia: A Study using the Revised Epilepsy Stigma Scale. *Seizure*. 2014;23(2):117-21.

13. Khan N, Jehan B, Khan A, Khan H. Audit of 100 cases of epilepsy in a tertiary care hospital. *Gomal J Medi Sci.* 2011;9(1):42-5.
14. Khalil R, Gul S, Naeem Z. Nature and extent of perceived stigma among epileptics in Pakistan. *Int J Res Med Sci.* 2016;4(9):3900-4.
15. Stake JE. Development and validation of the six-factor self-concept scale for adults. *Educational and Psychological Measurement.* 1994;54(1):56-72.
16. Rosenberg, M. *Society and the adolescent self-image.* New Jersey: Princeton University Press. 1994.
17. King M, Dinos S, Shaw J, Watson R, Stevens S, Passeti F, et al. The Stigma Scale: development of a standardized measure of the stigma of mental illness. *Br J Psychiatry.* 2007;190:248-54.
18. Berkman LF, Syme SL. Social networks, host resistance, and mortality: a nineyear follow-up study of Alameda County residents. *Am J Epidemiol.* 1979;109(2):186-204.
19. Biftu BB, Dachew BA, Tiruneh BT. Perceived Stigma and Associated Factors among people with Epilepsy at Gonda University Hospital, Northwest Ethiopia: a cross-sectional institution-based study. *Afri Health Sci.* 2015;15(4):1211-9.
20. Ryu HU, Lee SA, Eom S, Kim HD. Perceived Stigma in Korean adolescents with Epilepsy: Effects of knowledge about epilepsy and maternal perception of Stigma. *Seizure.* 2014;24:38-43.
21. Luna J, Nizard M, Becker D, Gerard D, Cruz A, Ratsimbazafy V, Dumas M, Cruz M, Preux PM. Epilepsy associated levels of perceived stigma, their associations with treatment, and related areas in Ecuador. *Epilepsy Behav.* 2017;68:71-7.
22. Pescosolido BA. The Stigma Complex. *Annual Review of Sociology.* 2015;41:87-116.
23. Kwong KL, Lam D, Tsui S, Ngan M, Tsang B, Lai TS, Lam SM. Self-esteem in Adolescents with epilepsy: Psychosocial and Seizure-related correlates. *Epilepsy Beh.* 2016;63:118-22.
24. Lim KS, Tan CT. Epilepsy Stigma in Asia: The Meaning and Impact of Stigma. *Neurology Asia.* 2014;19:1-10.
25. Shi Y, Wang S, Ying J, Zhang M, Liu P, Zhang H, Sun J. Correlates of Perceived Stigma for people living with epilepsy: A meta-analysis. *Epilepsy Behav.* 2017;70:198-03.

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