



On the experience of stigma by persons with epilepsy in Sweden and Iran—A comparative study



Lars Forsgren^a, Helia Ghanean^{b,c,*}, Lars Jacobsson^b, Jorg Richter^d

^a Department of Neurology, Umea University, Sweden

^b Department of Psychiatry, Umea University, Sweden

^c Tehran Medical University, Tehran, Iran

^d Medical Faculty, University of Oslo, Norway

ARTICLE INFO

Article history:

Received 14 January 2013

Received in revised form 2 May 2013

Accepted 27 May 2013

Keywords:

Epilepsy

Internalized stigma

Iran

Perceived stigma

Sweden

ABSTRACT

Purpose: The aim of this paper is to compare the experience of stigma by persons with epilepsy in Sweden and Iran.

Method: An adapted version of the Internalized Stigma of Mental Illness Scale was completed by 130 persons with epilepsy in Tehran and 93 patients at a neurology clinic in Sweden.

Results: The Swedish subjects reported a significantly lower level of experienced stigmatization than the Iranian patients, which we think is an effect of a more individualized medical treatment and a longer experience of health education in the Swedish society.

Conclusion: Improved seizure control, legislative measures and health education are major contributory factors for stigma reduction in a society as regards epilepsy and probably also other medical conditions.

© 2013 British Epilepsy Association. Published by Elsevier Ltd. All rights reserved.

1. Introduction

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. As effective treatments have been developed and the knowledge about the nature of the disorder has increased in the general population, especially in high income countries with well developed health care and a general high level of education, the level of stigma attached to the disorder has slowly decreased.¹ There is still, however, a lack of knowledge about epilepsy in many persons in Sweden. As many as 83% did not know what to do if a person gets a generalized seizure and there is still a lot of stigma attached to epilepsy according to a Swedish study.² For example, when findings from this study were reported in the biggest national newspaper, they wrote about “epileptics” in the title of the presentation – as if the person would be his/her disorder!

Part of the stigma complex is the experience of stigma by the persons suffering from epilepsy and what has been described as “internalized stigma” – “the devaluation, shame, secrecy and

withdrawal triggered by applying negative stereotypes to oneself”.³ Ritsher et al.³ have developed a questionnaire Internalized Stigma of Mental Illness (ISMI) to study internalized stigma related to mental disorders, which we found useful also related to epilepsy. This concept of internalized stigma has also been discussed by Muhlbaum.⁴

The aim of the study was to compare the experience of stigmatization of patients suffering from epilepsy in Iran and Sweden. Sweden is a modern western welfare state with a well-educated population and a developed health care system. Iran is a middle income country with a quite well developed health care system, but a different socio-cultural milieu as an Islamic state with strict adherence to Islamic teaching and tradition. Islamic culture is interesting from the point of view that it might represent a less stigmatizing cultural milieu because of the possible interpretation derived from the Holy Quran that, whatever happens to a person, it might be the will of God and not necessarily a punishment of God. This implies that persons suffering from different disorders should be treated with respect and tolerance.⁵

We hypothesized that (a) patients from both cultures reflect on stigmatization in terms of similar constructs expressed by a similar factor structure of questionnaire data; and that (b) the stigmatization experience among Swedish patients is less intensive than among Iranian patients. The findings might shed light on the question of how to reduce stigma because of epilepsy and other medical disorders.

* Corresponding author at: Department of Psychiatry, Umea University, SE-90187 Umea, Sweden. Tel.: +0046907865000.

E-mail addresses: lars.forsgen@neuro.umu.se (L. Forsgren), helia.ghanean@psychiat.umu.se, ghaneanh@hotmail.com, dir@raspina.com (H. Ghanean), lars.jacobsson@psychiat.umu.se (L. Jacobsson), jrichterj@web.de (J. Richter).

2. Materials and methods

2.1. Sample

130 Iranian persons attending an epilepsy clinic at one of the general hospitals in Tehran and members of the Epilepsy association in Tehran constituted the Iranian sample.⁶ The Swedish subjects were 100 consecutive outpatients attending the Neurology clinic at the University Hospital in Umeå during four months, who were asked to complete the questionnaire on stigma. Completed questionnaires were returned from 93 patients. Some socio-demographic data on the patients are presented in Table 1.

The samples do not differ related to gender; but, the Iranian patients were, on average, significantly younger ($\chi^2(3) = 23.83$; $p < .001$) and had more years of education ($\chi^2(1) = 17.46$; $p < .001$) than the Swedish patients.

2.2. Measures

An adapted version of ISMI³ was completed by the patients. This questionnaire was originally developed to assess experienced stigmatization of patients suffering from mental illness. It consists of 29 items to be rated based on a 4-point-Likert-type scale (1 = strongly disagree to 4 = strongly agree) implying that high scores reflect severe stigmatization. The original instrument has five a priori theory driven subscales labelled as Alienation, Stereotype endorsement, Perceived discrimination, Social withdrawal, and Stigma resistance. ISMI has a strong internal consistency ($\alpha = 0.90$) and test-retest reliability ($r = 0.92$) as reported by Ritscher et al.³ We adapted the items to epilepsy for our purpose by replacing “mental illness” with “epilepsy” in the questionnaire by permission from Dr. Ritscher. This adapted questionnaire will be called ISEP (Internalized Stigma of Epilepsy) in the following text.

McGlone et al. made a study in 2009⁷ comparing our scale ISMI with commonly used Felt Stigma Scale (FSS) scale. They concluded that ISMI was “A reliable and valid measure in adults with Epilepsy”. They also noted “an important advantage over the brief FSS in its multi-dimensionality”.

In the end of the questionnaire there was an open-ended question on own experiences of being discriminated because of their epilepsy.

The questionnaire was translated back and forth from English into Farsi and Swedish.

2.3. Statistics

Cronbach's alpha as reliability indicator was calculated based on the originally proposed factor structure by country. A factor analysis (principal axis factoring; Promax rotation with Kaiser normalization) limited to a five-factor solution was separately

Table 1

Age and years of education by gender (n%).

	Iran			Sweden		
	Females	Males	Total	Females	Males	Total
N	61/48.0	66/52.0	127	47/51.6	44/48.4	93
Age categories						
≤25 years	22/36.1	29/43.9	51/40.2	15/31.9	9/20.5	24/25.8
26–40 years	30/49.2	28/42.4	58/45.7	15/31.9	15/34.1	31/33.3
41–64 years	9/14.8	8/12.1	17/13.4	14/29.8	13/29.5	27/29.0
≥65 years	0	1/1.5	1/0.7	3/6.4	7/15.9	11/11.9
Years of education						
≤12 years	18/30.5	33/51.6	51/40.2	27/58.7	35/83.3	63/71.0
≥12 years	41/69.5	31/48.4	72/59.8	19/41.3	7/16.7	27/29.0

conducted on the data of both samples. To compare the structure in the data between the samples factor congruence coefficients were calculated by procrustes rotation method. A congruence coefficient $\geq .80$ was interpreted as indicative for factor congruence.⁸ Factor congruence coefficients were calculated for the comparison of the factor structure of the Iranian and the Swedish data with the “ideal matrix” based on the original subscale structure (with a factor loading of 1 on the factor the items should belong to and a loading of 0 on the other factors).

Mean scores were compared between the samples on item-level by *t*-test for independent samples. Only significant differences with a *t*-score ≥ 5.00 ; $p \leq .0001$ were evaluated as substantial and are reported.

2.4. Ethics

The studies were approved by the appropriate research Ethics committees in Tehran and Umeå and performed according to the principles of the Helsinki declaration. The questionnaires were completed anonymously.

3. Results

Internal consistency in terms of Cronbach's alpha was acceptable to good for most of the factors based on the originally proposed structure of the questionnaire except for the scale ‘Stigma resistance’ in the Iranian sample and for the scale ‘Stereotype endorsement’ in the Swedish sample (Table 2).

Neither the factor structure of the Iranian, nor the structure of the Swedish data supported factor congruence with the original subscale structure of the Internalized Stigma of Mental Illness Scale³ by coefficients above the requested level (Table 3). Additionally, we could not find factor congruence between the data of our two samples.

Therefore, we decided to compare data on the item-level. Swedish patients with epilepsy, on average, reported substantial less stigmatization compared to the Iranian with significantly lower scores on 16 of the 29 items (each with $t \geq 5.0$; $p \leq .0001$). The biggest difference was found for the item “People discriminate against me because I have epilepsy” ($t = 11.84$; $p \leq .0001$). The items with significant differences were; all items of the subscale “Discrimination experience”, five of the seven items of subscale “Stereotype endorsement”, five of the six items of subscale “Social withdrawal”, and one of the five items of “Alienation”. The Iranian and the Swedish subjects did not differ on any of the items that originally were supposed to be indicative for Stigma resistance.

Table 2

Cronbach's alpha of the factor scores.

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Overall
Iranians	.80	.77	.83	.83	.54	.92
Swedishs	.72	.37	.77	.80	.60	.86

Factor 1: discrimination experience; Factor 2: stereotype endorsement; Factor 3: social withdrawal; Factor 4: alienation and Factor 5: stigma resistance.

Table 3

Factor congruence coefficients.

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Sweden versus original	.65	.47	.52	.65	.79
Iran versus original	.58	.73	.54	.42	.51
Sweden versus Iran	.82	.54	.57	.35	.57

Factor 1: discrimination experience; Factor 2: stereotype endorsement; Factor 3: social withdrawal; Factor 4: alienation and Factor 5: stigma resistance.

Download English Version:

<https://daneshyari.com/en/article/10309730>

Download Persian Version:

<https://daneshyari.com/article/10309730>

[Daneshyari.com](https://daneshyari.com)