



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



Lars Forsgren<sup>a</sup>, Helia Ghanean<sup>b,c,\*</sup>, Lars Jacobsson<sup>b</sup>, Jorg Richter<sup>d</sup>

<sup>a</sup> Department of Neurology, Umea University, Sweden

<sup>b</sup> Department of Psychiatry, Umea University, Sweden

<sup>c</sup> Tehran Medical University, Tehran, Iran

<sup>d</sup> 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.

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## 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.<sup>1</sup> 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.<sup>2</sup> 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”.<sup>3</sup> Ritsher et al.<sup>3</sup> 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.<sup>4</sup>

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.<sup>5</sup>

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](mailto:lars.forsgen@neuro.umu.se) (L. Forsgren), [helia.ghanean@psychiat.umu.se](mailto:helia.ghanean@psychiat.umu.se), [ghaneanh@hotmail.com](mailto:ghaneanh@hotmail.com), [dir@raspina.com](mailto:dir@raspina.com) (H. Ghanean), [lars.jacobsson@psychiat.umu.se](mailto:lars.jacobsson@psychiat.umu.se) (L. Jacobsson), [jrichterj@web.de](mailto: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.<sup>6</sup> 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 ISMI<sup>3</sup> 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.<sup>3</sup> 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 2009<sup>7</sup> 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.<sup>8</sup> 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  $\geq 5.00$ ;  $p \leq .0001$  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 Scale<sup>3</sup> 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.

**Table 4**  
10 items with highest means.

Iran	Sweden
24 Living with epilepsy has made me a tough survivor <sup>*</sup> ( $x=2.73$ )	14 I feel comfortable being seen in public with a person who is known to have epilepsy <sup>*</sup> ( $x=2.91$ )
21 People without epilepsy could not possibly understand me <sup>*</sup> ( $x=2.53$ )	24 Living with epilepsy has made me a tough survivor <sup>*</sup> ( $x=2.30$ )
3 People discriminate against me because I have epilepsy <sup>**</sup> ( $x=2.51$ )	21 People without epilepsy could not possibly understand me <sup>*</sup> ( $x=2.05$ )
11 I don't talk about myself much because I don't want to burden others with my epilepsy <sup>*</sup> ( $x=2.45$ )	26 In general, I am able to live my life the way I want to ( $x=1.93$ )
15 People often patronize me, or treat me like a child, just because I have an epilepsy <sup>**</sup> ( $x=2.40$ )	11 I don't talk about myself much because I don't want to burden others with my epilepsy <sup>*</sup> ( $x=1.82$ )
14 I feel comfortable being seen in public with a person who is known to have epilepsy <sup>*</sup> ( $x=2.36$ )	17 Having epilepsy has spoiled my life ( $x=1.67$ )
12 Negative stereotypes about epilepsy keep me isolated from the "normal" world ( $x=2.29$ )	27 I can have a good, fulfilling life, despite my epilepsy ( $x=1.66$ )
28 Others think I can't achieve much in life because I have epilepsy <sup>**</sup> ( $x=2.28$ )	16 I am disappointed in myself for having epilepsy ( $x=1.63$ )
22 People ignore me or take me less seriously just because I have epilepsy <sup>**</sup> ( $x=2.22$ )	5 I am embarrassed or ashamed that I have epilepsy ( $x=1.59$ )
19 Because I have epilepsy I need others to make most decisions for me <sup>**</sup> ( $x=2.18$ )	29 Stereotypes about epilepsy apply to me ( $x=1.59$ )

<sup>\*</sup> Items under the first ten in both samples.

<sup>\*\*</sup> Items with significant differences between both samples.

**Table 5**  
10 items with lowest means.

Iran	Sweden
6 People with epilepsy shouldn't get married <sup>***</sup> ( $x=1.74$ )	6 People with epilepsy shouldn't get married <sup>***</sup> ( $x=1.09$ )
18 People can tell that I have epilepsy by the way I look <sup>***</sup> ( $x=1.76$ )	4 I avoid getting close to people who don't have epilepsy to avoid rejection <sup>**</sup> ( $x=1.18$ )
26 In general, I am able to live my life the way I want to ( $x=1.81$ )	18 People can tell that I have epilepsy by the way I look <sup>***</sup> ( $x=1.19$ )
27 I can have a good, fulfilling life despite my epilepsy ( $x=1.81$ )	20 I stay away from social situations in order to protect my family or friends from embarrassment <sup>*</sup> ( $x=1.22$ )
1 I feel out of place in the world because I have epilepsy ( $x=1.82$ )	19 Because I have epilepsy I need others to make most decisions for me <sup>**</sup> ( $x=1.23$ )
10 People with epilepsy cannot live good, rewarding life ( $x=1.85$ )	25 Nobody would be interested in getting close to me because I have epilepsy <sup>***</sup> ( $x=1.26$ )
25 Nobody would be interested in getting close to me because I have epilepsy <sup>***</sup> ( $x=1.87$ )	9 I don't socialize much because I don't want to burden others with my epilepsy <sup>***</sup> ( $x=1.27$ )
5 I am embarrassed or ashamed that I have epilepsy ( $x=1.89$ )	3 People discriminate against me because I have epilepsy <sup>**</sup> ( $x=1.28$ )
20 I stay away from social situations in order to protect my family or friends from embarrassment <sup>***</sup> ( $x=.90$ )	23 I can't contribute anything to society because I have epilepsy <sup>**</sup> ( $x=1.30$ )
9 I don't socialize much because I don't want to burden others with my epilepsy <sup>***</sup> ( $x=1.93$ )	22 People ignore me or take me less seriously just because I have epilepsy <sup>**</sup> ( $x=1.30$ )

<sup>\*\*</sup> Items with significant differences between both samples.

<sup>\*\*\*</sup> Items both, under the last ten items in both samples and significant differences between the samples.

The patients from both countries evaluated that their epilepsy had made them "tough survivors", the item with the highest mean score in both samples. There were another three common items under the ten items indicating most severe stigmatization. However, the mean score of five items in the Iranian data was significantly higher than in the Swedish data (each with  $t \geq 5.0$ ;  $p \leq .0001$ ) (Table 4).

These ten items originally belonged to the different original subscales; four to "Discrimination experience", two each to "Social withdrawal" and "Stigma resistance" and one each to "Alienation" and "Stereotype endorsement" in the Iranian data and four each to "Alienation" and "Stigma resistance" and one each to "Stereotype endorsement" and "Social withdrawal" in the Swedish data.

The patients from both countries showed the highest disagreement to the item stating that patients with epilepsy should not marry; but the Swedish disagreed significantly more than the Iranians (Table 5).

Five of the ten items with the lowest mean score were the same in both samples. However, the scores of these five and of additional seven items were significantly lower in the Swedish than in the Iranian data. The ten items with the lowest mean scores were indicative to the original subscales "Stereotype endorsement" (three items), "Stigma resistance", "Social withdrawal" and

"Alienation" (two items), and "Discrimination experience" (one item) for the Iranian sample, whereas these items of the Swedish originally belonged to subscale "Discrimination experience" and "Social withdrawal" (three items each) and "Stereotype endorsement" (four items).

The Iranian subjects were very active in responding to the open-ended question. Many expressed a need to hide their disorder and problems to become employed. In the Swedish sample, comments were less common and mainly dealt with medical aspects. A few reported on problems with getting job and a need for providing the general public with more information about the disorder. Several patients reported that they had no experience of being discriminated because of their epilepsy.

#### 4. Discussion

The two samples were both convenience samples. The Iranian subjects were recruited from a specialized clinic for epilepsy and members of the Iran epilepsy association indicating a rather well-treated and well-informed group of persons suffering from epilepsy. The Swedish sample consists of patients to a specialized university clinic. Patients who were considered not being able to respond to the questionnaire because of disabilities (for example,

**Table 6**

Comparison of subscale means and SD between patients suffering from epilepsy in Sweden and in Tehran.

Subscales	ISEP Iran (N=130)	ISEP Sweden (N=93)
Alienation	2.06 (0.64)	1.66 (0.68)
Stereotype endorsement	1.96 (0.62)	1.32 (0.35)
Discrimination	2.26 (0.71)	1.33 (0.05)
Social withdrawal	2.10 (0.69)	1.37 (0.50)

intellectual disabilities) were excluded from this investigation. The Swedish sample probably consisted of somewhat more complicated cases than the general epilepsy population. A small proportion of seizure free patients or with low seizure frequency is treated by general practitioners and specialists in internal medicine in the region. The investigated Iranian patients had the opportunity to ask questions and get support to fill in the questionnaire by one of the authors (H.G.) whilst the Swedish sample was asked to fill in the questionnaire by their own. Overall, we assume that the two samples are reasonably similar with regard to severity of the disorder and level of medical care. The differences as regards age and educational level between the two samples we do not think have a major impact on the results as our main interest is a global evaluation of the level of experienced stigma in the two settings.

As regards the questionnaire it is apparent that we did not find a similar factor structure in the two samples and this was not really expected. The subscales in the original paper were basically theory driven and the team who developed the scale did not even find a complete congruence with the factors derived in a factor analysis. The authors conclude that “it is most parsimonious to conceptualize the ISMI as measuring a single construct”. We present the original subscales’ mean scores to be able to compare the results from Iran and Sweden (Table 6). Based on the original subscales the level of stigmatization is much lower in the Swedish sample (we have not used the resistance scale as this is considered less consistent even by the constructors of the scale) than in the Iranian sample reflecting the above reported findings on item-level.

The results of the single item analysis as well as the subscales show a significant difference between the two samples; the Swedish patients reporting less internalized stigma according to the used instrument than the Iranian sample. This was expected (hypothesis b) for two main reasons. Even if the health care system in Tehran is well developed it may be that the patients at the university neurology clinic in Sweden have a more individualized treatment and follow-up than the Iranian patients. The Iranian patients often visit the clinic in groups; and the time devoted to each individual is much shorter than that available for the Swedish patients. It is also reasonable to assume that the range of available antiepileptic drugs in Sweden is wider and more diversified than in Iran. Furthermore, the monitoring of the patients at the Swedish clinic is probably more individualized than that of the Iranian. Patients with different disorders often are organized in patients’ organizations in Sweden, e.g. an epilepsy organization. This national organization provides information and support to their members together with their local societies, activities likely to reduce stigma. A second main explanation might be the general high level of education and knowledge in the Swedish society

about epilepsy. Even if there is still a need for more information to the general public about epilepsy and how to recognize and treat the disorder it is reasonable to assume that the Swedish public has a longer experience of health education than the Iranian. However, there has not been any special national or regional campaign to inform about epilepsy in Sweden and to reduce stigma. Internationally, for example, the WHO has launched special campaigns.<sup>9</sup> The experience with different types of anti-stigma campaigns is that they might have a temporary effect, but in the long run it is probably more important to raise the general educational level in the population and make legislative measures.<sup>10</sup> The most important measure, however, is probably to improve the availability of a high quality medical care including diagnosis, medical treatment, careful monitoring of the disorder and education to patients and their families on various aspects of the disorder. Improved seizure control is of major importance for quality of life and stigma reduction.<sup>10–12</sup> The better integrated individuals who suffer from epilepsy are in the family and in the society as a whole, the less stigmatizing this disorder will be.

In conclusion the study reveals a significantly lower level of experienced stigmatization in the Swedish subjects compared to the Iranian which might be the result of a more individualized medical treatment and a longer experience of health education in the Swedish society. The findings will be of interest when discussing stigma reduction because of medical disorders in a society.

## Acknowledgements

The authors are grateful for the support of professor Joghatai, Iran University of Medical Sciences, Tehran, Iran Epilepsy Association, Dr Babak Zamani, Rasoul Hospital and registered nurse Greta Hietala, University Hospital, Umea.

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