Self-perception of stigma in persons with epilepsy in Tehran, Iran

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ABSTRACT

Epilepsy is one of the most stigmatizing medical conditions worldwide. It could be argued that the problem of stigma and discrimination might be different in an Islamic culture. A cross-sectional study of 130 patients with epilepsy was performed using the Internalized Stigma of Mental Illness (ISMI) questionnaire that was adapted for epilepsy. The questionnaire contained 29 items on a 4-point scale in addition to an open-ended question about experience of discrimination. An average score above the midpoint (2.5) is suggested to indicate a high level of stigma. Approximately 23.7% of the patients reported a score above the midpoint. Unemployment and low education were significantly associated with a high level of internalized stigma. Although epilepsy can be effectively treated, patients in Tehran still experience much stigma. For this reason, strategies for reducing self-perception of stigma should be included in a treatment plan.

1. Introduction

Stigma and discrimination resulting from certain medical conditions are global phenomena. Epilepsy, leprosy, mental disorders, and HIV/AIDS are some of the most stigmatizing disorders worldwide [1]. However, epilepsy and HIV/AIDS are good examples of disorders that have become less stigmatizing in high-income Western countries because of increased knowledge and modern treatment opportunities. However, in countries transitioning to a more modern society, there is still stigma associated with epilepsy [2,3].

There are a number of studies that have been mainly performed in Western countries that describe the attitudes towards epilepsy and people with this disorder as well as the experience of people with epilepsy with stigma and discrimination [4–6]. In addition, there are a number of studies from low- and middle-income countries focusing mainly on the attitudes of the general public towards epilepsy [7–11].

The self-perception of those suffering from epilepsy is as important as public attitudes towards epilepsy and those with epilepsy. A general model for stigma development is to look at stigma as a process starting with a deviance in a person who exhibits a behavior felt as deviant and withdrawal triggered by applying negative stereotypes to the inflicted person himself. The impact of the illness also affects the family and the community indirectly. Life opportunities become increasingly limited because of the physical hazards, the unpredictability of the disorder, and the associated consequences of stigma.

Ritsher and coworkers have developed a concept of internalized stigma with regard to persons suffering from mental disorders. They describe internalized stigmatization as “the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to one self” [12]. This aspect of internalized stigma contributes to an individual’s feeling of being different, which can counteract positive effects of undergoing treatment. Reducing the self-perception of epilepsy as something devaluing and shameful could be an important goal of the treatment strategy [3].

The perceptions and attitudes associated with epilepsy might be different in a Muslim country. Islam, which is the largest religion worldwide after Christianity, contains some interesting elements on its teachings about persons suffering from different types of disorders. One underlying idea is that whatever happens to a person may be the will of God and not necessarily a punishment for something bad they have done. This suggests that persons suffering from disorders should be treated with respect and tolerance. Muslims refer to the holy Quran in all aspects of their life, and there are some chapters in the Quran...
that deal with health and sickness, rules of hygiene, and medical concepts in general. These chapters might make a difference in the public perception of people suffering from epilepsy [13].

In the Persian culture, one of the first references of epilepsy was recorded in the textbook Avesta, which was most likely compiled during the 6th century B.C. [14]. In it, a god states that persons with epilepsy should not make an offering in honor of him. According to a study by Baker et al., which described the quality of life of individuals with epilepsy, more than one-third of all respondents felt stigmatized by their epilepsy in Iran, the Persian Gulf, and the Near East [15]. One example of stigmatization is an unwillingness to marry or employ a person with epilepsy, which is reasonably reminiscent of a more traditional perception of epilepsy based on prescientific ideas about the nature of the disorder.

Because epilepsy is one of the most stigmatizing medical conditions worldwide, it can be used as a model for studying the development of stigma and how to combat stigma and the discrimination resulting from any illness. However, it is apparent that the stigma and discrimination resulting from epilepsy have decreased in countries where modern effective treatment is available [16]. These treatments combined with the increased knowledge of the general population about the nature of the disorder are most likely the main reasons for this positive development. In such countries, epilepsy is now slowly becoming more like any other medical condition. The aim of this study is to look into the experience of internalized stigma in persons suffering from epilepsy in Tehran.

2. Methods

The study was conducted in Tehran, which has approximately 8 million inhabitants (with greater Tehran having a population of approximately 12 million). The health-care system is well-developed, and, in most cases, all citizens have access to good quality medical care. In addition, Iran is an Islamic republic with strict adherence to Islamic teachings and traditions. The majority of the rather young and well-educated Iranian population belongs to the Shia Islamic group.

A total of 130 individuals with epilepsy were recruited from two different institutions and agreed to participate in this study. One group came from the epilepsy outpatient clinic of the Iran Medical University at Rasoul Hospital, which covers the northern and western part of the city. The Iran Epilepsy Association helped by introducing us to their members at their annual meeting held in the winter of 2008. The subjects were given a questionnaire to fill out and were subsequently asked an open-ended question regarding their experience of stigma and discrimination.

The Internalized Stigma of Mental Illness (ISMI) scale developed by Ritsher et al. evaluates internalized stigmatization, which reflects the internal experiences related to stigmatization of people suffering from a mental disorder [12]. With the permission of Ritsher et al., this instrument was used to study internalized stigma of persons with epilepsy.

The ISMI scale is a self-report questionnaire, and it evaluates subjective stigmatization experiences within the framework of five subscales: “Alienation” with 6 items, “Stereotype Endorsement” with 7 items, “Discrimination Experience” with 5 items, “Social Withdrawal” with 6 items, and “Stigma Resistance” with 5 items. All items are measured by a 4-point Likert-type scale from “strongly disagree” to “strongly agree” (1 = strongly disagree to 4 = strongly agree).

The “Alienation” subscale measures the subjective experience of being less than a full member of society. The “Stereotype Endorsement” subscale measures the degree that respondents agree with common stereotypes regarding people with epilepsy. The “Discrimination Experience” subscale is composed of five items intended to capture the respondent’s perception of the way that he or she currently is being treated by others. The “Social Withdrawal” subscale consists of statements like “I don’t talk about myself much because I don’t want to burden others with my epilepsy”. The “Stigma Resistance” subscale measures the degree of resistance towards being stigmatized or remain unaffected by internalized stigma.

The ISMI scale was adapted to be used to study patients suffering from epilepsy by changing the wording in the questionnaire from “mental illness” to “epilepsy”. The ISMI scale was translated using forward and backward translation from English to Farsi by psychologists and psychiatrists who have a strong command of the English language. The resulting questionnaire covering epilepsy will be called ISEP (Internalized Stigma of Epilepsy) in the subsequent text.

Some sociodemographic data included in the questionnaire were gender, age, marital status, education, and occupation. An open-ended question was also administered at the end of the questionnaire to learn about each patient’s personal experience with discrimination due to their epilepsy.

A pilot study was conducted with 30 individuals to determine the feasibility and reliability of the Farsi version of the ISEP. The questionnaire pilot study resulted in an internal consistency of 0.87. Overall, the items were well understood.

The internal consistency of the questionnaire was assessed by Cronbach’s alpha coefficient, and an alpha equal to or greater than 0.70 was considered satisfactory. We used chi-square tests for comparison of the midpoint of the scale to the overall score by demographic variables. A significant level was considered p < 0.05.

The study was approved by the Tehran Mental Health Research Institute and by the research ethics committee of the Iran Epilepsy Association of Iran Medical University.

3. Results

Some of the background data on the study population are reported in Table 1. The mean age was 29 years with approximately equal gender participation. There were no differences between males and females regarding age distribution and marital status (the majority of participants were single in both genders). Females had higher educational level, but a great majority of them were unemployed (8 of 52 were employed).

The internal consistency score for the entire scale of ISEP was 0.91, the score for the Alienation subscale was 0.67, the Stereotype Endorsement subscale score was 0.81, the Discrimination Experience subscale score was 0.80, the Social Withdrawal subscale score was 0.84, and the Stigma Resistance subscale score was 0.47.

The responses to the different items in the questionnaire are reported in Table 2.

Table 1  Sociodemographic background in percentages (N = 130).

|                        | Males (N = 67) | Females (N = 63) | Pearson chi-square |
|------------------------|----------------|------------------|--------------------|
| **Age**                |                |                  |                    |
| ≤25 years              | 43.9           | 36.1             | n.s.               |
| 26–40 years            | 42.4           | 49.2             |                    |
| ≥40 years              | 13.7           | 14.7             |                    |
| Missing data (3)       |                |                  |                    |
| **Education**          |                |                  |                    |
| ≤12 years at school    | 49.2           | 30.5             | p < 0.05           |
| >12 years at school    | 50.8           | 69.5             |                    |
| Missing data (9)       |                |                  |                    |
| **Marital status**     |                |                  |                    |
| Single                 | 67.2           | 66.7             | n.s.               |
| Ever married           | 32.8           | 33.3             |                    |
| Missing data (6)       |                |                  |                    |
| **Occupation**         |                |                  |                    |
| Employed               | 43.9           | 13.3             | p < 0001           |
| Unemployed             | 56.1           | 86.7             |                    |
| Missing data (4)       |                |                  |                    |
Table 2: Prevalence of internalized stigma in percentages (N = 130).

|                       | Strongly disagree | Disagree | Agree | Strongly agree |
|-----------------------|------------------|----------|-------|----------------|
| Alienation            |                  |          |       |                |
| I feel out of place in the world because I have epilepsy | 48              | 29       | 16    | 7              |
| Having epilepsy has spoiled my life | 31              | 41       | 17    | 11             |
| People without epilepsy could not possibly understand me | 13              | 32       | 43    | 12             |
| I am embarrassed or ashamed that I have epilepsy | 42              | 31       | 18    | 9              |
| I am disappointed in myself for having epilepsy | 35              | 38       | 19    | 8              |
| I feel inferior to others who don’t have epilepsy | 33              | 37       | 24    | 6              |
| stereotype endorsement |                |          |       |                |
| Stereotypes about epilepsy apply to me | 24              | 45       | 21    | 10             |
| People can tell that I have epilepsy by the way I look | 44              | 40       | 12    | 4              |
| Persons with epilepsy tend to be violent | 32              | 34       | 23    | 11             |
| Because I have epilepsy, I need others to make most decisions for me | 30              | 34       | 26    | 10             |
| People with epilepsy cannot live a good, rewarding life | 43              | 36       | 14    | 7              |
| Persons with epilepsy shouldn’t get married | 50              | 30       | 12    | 6              |
| I can’t contribute anything to society because I have epilepsy | 33              | 38       | 21    | 8              |
| discrimination experience |                 |          |       |                |
| People discriminate against me because I have epilepsy | 16              | 28       | 44    | 12             |
| Others think that I can’t achieve much in life because I have epilepsy | 27              | 28       | 34    | 11             |
| People ignore me or take me less seriously just because I have epilepsy | 26              | 35       | 30    | 9              |
| People often patronize me or treat me like a child just because I have epilepsy | 24              | 29       | 30    | 17             |
| Nobody would be interested in getting close to me because I have epilepsy | 40              | 44       | 11    | 5              |
| social withdrawal |                      |          |       |                |
| I don’t talk about myself much because I don’t want to burden others with my epilepsy | 22              | 27       | 33    | 18             |
| I don’t socialize as much as I used to because my epilepsy might make me look or behave “weird” | 39              | 33       | 23    | 5              |
| Negative stereotypes about epilepsy keep me isolated from the “normal” world | 22              | 35       | 34    | 9              |
| I stay away from social situations in order to protect my family or friends from embarrassment | 38              | 40       | 16    | 6              |
| Being around people who don’t have epilepsy makes me feel out of place or inadequate | 34              | 39       | 21    | 6              |
| I avoid getting close to people who don’t have epilepsy to avoid rejection | 36              | 34       | 21    | 9              |
| Stigma resistance (reverse-coded items) |                  |          |       |                |
| I feel comfortable being seen in public with a person who is known to have epilepsy | 19              | 41       | 25    | 15             |
| In general, I am able to live my life the way I want to | 36              | 50       | 11    | 3              |
| I can have a good, fulfilling life despite my epilepsy | 40              | 44       | 12    | 4              |
| People with epilepsy make important contributions to society | 27              | 50       | 18    | 5              |
| Living with epilepsy has made me a tough survivor | 7               | 29       | 45    | 19             |

Kitsch et al. defined persons with high levels of internalized stigma as having an average score above the 2.5 midpoint on the possible range on a scale of 1–4. Using the midpoint of the scale shows that a total of 23.7% of individuals had a score equal to or above 2.5. For the five subscales, using the midpoint of the scale indicates that 23.1% of individuals had a score equal to or above 2.5 for Social Withdrawal, 17.7% for Stigma Resistance, 19.2% for Alienation, 17.7% for Stereotype Endorsement, and 34.6% for Discrimination Experience. There were no differences between males and females with regard to the means of the five subscales.

Persons with less than a high school degree or who were unemployed reported a significantly higher experience of stigma. The other sociodemographic variables did not show any differences in regard to the experience of stigma. Married and widowed persons had higher scores than singles on the Stigma Resistance subscale, which suggests that being married or widowed makes a person more resistant towards stigmatization.

Almost all respondents were eager to discuss their experience of living with epilepsy. The majority of the responses fitted well into the different subscale concepts. Some examples of responses that show feelings of alienation are the following: “Comparing me and my cousin in family they like her more than me”, “In this society, we have no rights as patients suffering from epilepsy”, and “My son’s friends don’t invite my son to their school gatherings”. An example of a response that indicates stereotype endorsement is “As regards society and job we cannot contribute”. Many responses dealt with discrimination experience such as the following: “They don’t invite us to parties as if we have leprosy”, “I wanted to marry this man, but his family didn’t agree and threatened to kill me if we married”, “In this job application they prefer not to choose patients with epilepsy”, and “They think we are insane”.

An example of a response that indicates social withdrawal is “I cannot become friend with others — I am scared to have an attack every moment”. Other responses include “I hide my seizure attacks” and “My family wants me to hide my disease before my marriage to fiancé and in-laws”. Examples of responses that indicate stigma include “I don’t talk about my disease; however, it is God’s will and it would be better by expressing it everywhere” and “I am a nurse and my colleagues understand me and don’t discriminate against me”.

4. Discussion

The ISMI questionnaire was originally developed to investigate experiences of stigma in mentally ill persons, but we also found the questionnaire useful in evaluating stigma due to epilepsy. The concepts examined by the questionnaire were easily understood by the patients. However, item number 24, “Living with epilepsy has made me a tough survivor”, was difficult to translate and to make comprehensible for the subjects in this study. In many cases, the premise behind item 24 had to be explained in further detail. Apart from item 24, all items were easily understood.

The questionnaire has been found to have good psychometric properties when used in patients with mental disorders, and this was similarly observed in the epilepsy version with high coefficient alpha scores for the whole questionnaire (0.91) and also for the different subscales except for the Stigma Resistance subscale (0.47), which is not quite consistent. There are other scales developed specifically to study the stigma of epilepsy, but as we had used the ISMI scale to study the experience of stigma due to mental illness in Iran, we thought it would be interesting to use this scale with regard to epilepsy to be able to compare the two conditions [2].

The study group consisted of persons suffering from epilepsy for a long time. Approximately half of them were patients at a special epilepsy clinic, and the other half were recruited from members of the Iran Epilepsy Association. We assumed that the patients included in the study were representative of a group of persons suffering from epilepsy. However, it is important to keep in mind that the overall group was rather young, well-educated, on medication, and living in Tehran. Compared to a group of randomly chosen inhabitants in Iran in an ongoing study of public perception of mental illness, this
group has a higher educational level, but they are more often single and unemployed. This might explain the picture of marginalization that is illuminated in the comments in the open-ended question. In addition, they are generally well-informed about their condition and illness. It would be interesting to study other Iranian ethnic groups as well as people living in rural areas where there could be differences in the knowledge level, the availability of effective treatments, and, potentially, the value system.

All the participants were very favorable to the study and expressed their appreciation at being given the initial opportunity, in many cases, to discuss their life with epilepsy. Many of the participants told their individual stories, and almost all of them had responses to the open-ended question at the end of the investigation. It is difficult to be explicit on the prevalence of stigma as there are no “normative” data — what is a high level or a low level of stigma? To address this question, we applied the example of the group that developed ISMI and used the midpoint of the scale as a possible level of high internalized stigma. Using the midpoint of the scale, we found that 23.7% of the respondents had an average score equal to or above 2.5 (on a 1–4 scale). The highest prevalence was reported for the Discrimination Experience (34.6%) and Social Withdrawal (23.1%) subscales.

Another way of determining the level of stigma would be to use the method suggested by Lysaker et al. [16], which also used the ISMI scale to study stigma in persons suffering from schizophrenia. They proposed that a score of two or less could be labeled “minimal stigma”, scores greater than two but less than 2.5 could be labeled as “mild stigma”, scores greater than 2.5 but less than 3 could be labeled as “moderate stigma”, and, finally, scores greater than 3 could be labeled as “severe stigma”. The resulting data from the study and data from a study of internalized stigma of mental illness in Tehran using this method are shown in Table 3 [17].

Table 3: A comparison of subscale means and stigma levels (in percentages) between patients suffering from epilepsy and patients suffering from mental disorders in Tehran.

| Stigma Level | ISPE (N = 130) | ISMI (N = 138) |
|--------------|----------------|----------------|
| Subscale means (SD) |                |                |
| Alienation    | 2.11 (0.69)    | 2.33 (0.73)    |
| Stereotype Endorsement | 1.97 (0.53) | 2.30 (0.60)    |
| Discrimination Experience | 2.25 (0.61) | 2.32 (0.67)    |
| Social Withdrawal | 2.10 (0.69) | 2.64 (0.83)    |
| Stigma Resistance | 2.14 (0.51) | 2.46 (0.39)    |
| Level of stigma |                |                |
| Minimal (<2)   | 45%            | 40%            |
| Mild (2–2.49)  | 28%            | 21%            |
| Moderate (2.5–3) | 16%         | 27%            |
| Severe (>3)    | 7%             | 12%            |

The willingness of the study participants to discuss their situation gives a strong indication that qualitative studies would be useful to investigate the thoughts surrounding epilepsy and the consequences for persons suffering from epilepsy with the aim of discovering ways to reduce stigma due to epilepsy. Over the past 15 years, the World Health Organization (WHO) has been working to reduce stigma resulting from epilepsy in low-income countries and in traditional societies [18]. One way is to inform the public about the causes of epilepsy and the ways to obtain effective treatment. There have also been epilepsy antistigma campaigns in some countries. Another equally important way to reduce the stigma associated with epilepsy is to improve treatments and the access to effective treatment. In addition, it would be important to improve the stigma-coping ability of persons suffering from epilepsy. There are some projects that use this approach in mentally ill persons, and it is reasonable to think that the same would be applicable to persons suffering from epilepsy. This approach could be an important tool not only for clinics working with patients suffering from epilepsy but also for their client organizations. It could be argued, however, that providing medicine to reduce the number of seizures in patients in resource-poor countries should be the priority for health providers and clinicians to help patients lead a normal life.

In this study, the participants were eager to discuss their self-perception of stigma rather than writing about it, which also shows that qualitative studies would be useful. In addition, the interviews revealed an important element in the participants’ interactions with health providers. None of the study participants complained about the provision of medicine and talked about the number of seizures and its complications, but they were concerned that they only had a few minutes to report their symptoms and collect their medicine in their routine visits to the clinics. They wanted to understand their medical condition better and to be understood by their health provider. During the collection of data in the outpatient clinic, the author observed that patients visited clinicians in groups rather than individually.

In conclusion, this study on stigma and discrimination experienced by persons with epilepsy in Tehran revealed a moderate level of stigma experiences. In contrast, in other countries in the region such as Pakistan and India, negative labels and perceptions of epilepsy have been described. However, epilepsy seems to be less stigmatizing compared to mental disorders in Tehran. The importance of Islamic thinking would be of interest for future studies. Qualitative studies would be valuable to gain a better understanding of how those with epilepsy perceive themselves and how they interact with society. It is obvious from this study that more work needs to be done to reduce the experience of stigma and discrimination in persons suffering from epilepsy in Iran.

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