



Stigmatization and social impacts of epilepsy in Turkey[☆]



Pelin Dogan Ak^{a,*}, Dilek Atakli^b, Burcu Yuksel^c, Betul Tekin Guveli^b, Huseyin Sari^b

^a Fatih Sultan Mehmet Education and Research Hospital, Neurology Department, Istanbul, Turkey

^b Bakirkoy Education and Research Hospital for Psychiatry, Neurology and Neurosurgery, Neurology Department, Istanbul, Turkey

^c Antalya Education and Research Hospital, Neurology Department, Antalya, Turkey

ARTICLE INFO

Article history:

Received 25 February 2015

Revised 6 May 2015

Accepted 7 May 2015

Available online 25 June 2015

Keywords:

Stigmatization

Epilepsy

Social impacts

ABSTRACT

Objective: Stigma associated with epilepsy has negative effects on psychosocial outcomes, affecting the lives of people with epilepsy (PWE). Obtaining basic social rights can be difficult compared to the general population. The aim of our study was to evaluate the perceived stigma among PWE and social attitude towards the disease and to compare the social measures with the general population in Turkey.

Method: A self-completed questionnaire consisting of demographic details and items about attitudes and perceived stigmatization was developed. Participants consisted of patients with various types of seizures who were randomly chosen from the epilepsy outpatient clinic. They were requested to complete the questionnaire. **Results:** Questionnaires were obtained from 330 PWE. One hundred forty individuals (43.3%) out of 323 reported feeling stigmatized.

The marriage and total fertility rates were below the national rates of Turkey. Keeping their epilepsy as a secret from society was prevalent. Although the education rate was not below the national rate, unemployment rate was high, and the average monthly wage was significantly lower than that of the general population. The majority thought that their families were protective towards them. Only 2 of the 330 participants were living alone.

Conclusion: The present study supports the perception of stigma associated with epilepsy and its negative impact on the lives of PWE in Turkey. Clearly, more research is needed to understand the reasons for stigma and how to decrease its impact.

© 2015 Elsevier Inc. All rights reserved.

1. Introduction

Epilepsy is a chronic neurological disorder without racial, national, or geographical boundaries. It has been estimated that it affects at least 50 million people worldwide. The burden of epilepsy may be due to psychological and social as well as physical consequences. Perceived stigmatization is a significant part of the hidden psychosocial burden of epilepsy since it has been related to low self-esteem, depression, anxiety, negative feelings, and impaired social skills [1–5]. Furthermore, people may experience social disqualification and discrimination as a consequence of stigma which lead to a lower quality of life. They are less often married, less educated, and more underemployed and unemployed than the general population [1,2,4–6]. Underachievement in school, restricted social activities and independence, parental overprotectiveness, and marital difficulties are documented [4].

Stigmatization is prevalent in epilepsy both in developed and in less developed countries [7–12]. It has also been shown to be more prevalent in this disease than in other chronic neurological diseases. A study compared epilepsy with migraine, another chronic neurological disorder with episodic attacks. Although people with migraine had lower quality of life and higher impact of illness values than people with epilepsy (PWE), there was no difference among the groups with regard to depression and low self-esteem and yet PWE were more stigmatized [13].

In this study, we investigated the perceived stigma among people with epilepsy in Turkey, social attitudes toward epilepsy and accessibility of social rights and compared these issues with the general population.

2. Material and methods

The study was approved by the Local Ethics Committee and designed as a cross-sectional, descriptive study.

A self-completed questionnaire which consisted of demographic details and items about negative attitudes and perceived stigmatization was developed. Demographic data included age, sex, marital status, level of education, employment status, and monthly income. Educational level was divided into three categories: (1) primary and secondary school (5–8 years), (2) high school (11 years), and (3) university.

[☆] Financial disclosure statement: None of the authors received any financial support for this clinical/scientific note.

* Corresponding author at: Fatih Mah, Yakacik Cad, Demirci Sok, Greenhill Villalari No. 8/B Sancaktepe, Istanbul, Turkey. Tel.: +90 505 6385031.

E-mail addresses: drpelindogan@hotmail.com (P.D. Ak), dilekatakli@hotmail.com (D. Atakli), dr.burcuy@hotmail.com (B. Yuksel), betulguveli@hotmail.com (B.T. Guveli), huseyinsari@gmail.com (H. Sari).

When analyzing employment status, subjects were divided into four categories: (1) employed, (2) unemployed, (3) currently studying, and (4) retired.

Participants consisted of patients with various types of seizures who were randomly chosen from the epilepsy outpatient clinic. Self-completed questionnaires were administered during the routine appointments, and patients were requested to complete part of the questionnaire while waiting for their appointments. Patients who could not fill out the provided questionnaire without help were excluded. The study was conducted between 2012 and 2014.

For statistical analysis, IBM SPSS Statistics, Version 21.0 was used.

3. Results

Questionnaires were obtained from 330 patients. However, some of the respondents did not answer one or more of the questions. The demographic data and items in the questionnaire are shown in Tables 1 and 2.

In the 330 patients with epilepsy, the mean age was 29.05 ± 11.31 years (range: 13–74); 64.8% were female and 35.2% were male.

The questions related to stigmatization revealed that 140 of the 323 patients (43.3%) reported feeling stigmatized. We did not find a significant correlation of the feeling of stigmatization with gender, marital status, or employment status of the respondents, whereas there was a correlation with educational level (Table 3).

Two hundred fifty-nine of the 327 patients (79.2%) thought that their families were more protective towards them, and only 2 of the 330 patients were living alone.

The marriage rate was 45.32% in the subgroup composed of 15–49-year-old female patients. We compared the spouses by their respective educational level and found that 20.58% of the patients had more years of education than their spouses. The total fertility rate, which refers to the average number of live births that a woman would be expected to have at her reproductive age (15–49 years), was 1.82. The married adults had an average number of 1.55 children, while married and single adults had 0.70.

Of the 125 married patients who were diagnosed before their marriage, 36.8% stated not disclosing their condition to their partners prior to the marriage. Furthermore, 56.0% of them stated that they did not tell the family members of their partners about their epilepsy before the marriage. The proportions of patients hiding their disease as a secret

during their schooling and while at work were 48.0% and 37.4%, respectively.

Only 9.9% of the 323 patients thought that the attitudes of people were getting worse when they learned about their epilepsy.

The unemployment rate was 44.2%. Moreover, 44.6% of the 222 patients stated that they had difficulty in finding a job at least once during their lives because of epilepsy, and 23.7% of 190 patients had been fired from a job because they had epilepsy.

Among the patients, 54.54% had a maximum education of 5–8 years of primary school, 17.87% had 11 years of high school, and 13.03% had university education. Of the 175 patients, 45.1% thought that their job was not appropriate for their level of education, and this rate was 38.46% among the patients with university education.

The average monthly wages of the patients in this study were divided into the following clusters: 0–300 USD (30.6%), 301–500 USD (40.9%), 501–750 USD (18.5%), 751–1000 USD (6.10%), and 1001 USD or more (3.90%).

4. Discussion

The purpose of this study was to examine the feeling of stigma among PWE living in Turkey, societal attitudes toward epilepsy, and how epilepsy affected their education, employment, economic status, and social functioning. The results demonstrate that the frequency of patients feeling stigmatized (43.3%) was similar to the frequency in some other studies [6,8,14–18].

In 1989, Scambler described two different types of stigma that are prevalent in PWE [19]. These were ‘enacted’ stigma, where PWE experienced actual discrimination because they had epilepsy and ‘felt’ stigma where PWE experienced the fear of ‘enacted stigma’. The latter means that stigma may be “felt” even if it does not actually exist. Additional research suggests that felt stigma may be more prevalent than enacted stigma [4,19,20]. In studies, factors such as the severity of disorder, frequency of seizures, age of onset, duration of epilepsy, number of years in school and employment status, and knowledge about the disease have been shown to be potentially associated with felt stigma [2,4,6,15,18].

The only demographic factor significantly associated with stigmatization in our study was level of education, which was shown to be negatively correlated with stigma, which has been reported previously in many studies [4,5,7]. Studies have demonstrated that insufficient knowledge may lead to increased feelings of stigma, emphasizing the importance of educational studies [15]. In a study by Mecarelli et al. assessing the awareness and attitudes of the public about epilepsy in Italy, poor education was shown to affect personal knowledge about epilepsy, which may lead to stigmatization [21].

Parental over protectiveness makes PWE feel less autonomous and reduces feelings of independence. It may interfere with the development of life skills and make PWE feel less confident and independent. This may lead to low self-esteem. In our study, the majority of the respondents thought that their families were more protective towards them. Additionally, almost all of the patients were living with their families. However, the proportion of one-person households was 8.6% in Turkey according to statistics [22]. We also observed the extreme protective attitudes of the families of our patients during the outpatient clinic interviews. We think that this may be due to Turkish social and cultural characteristics, since, according to statistics in Turkey, 52.1% of adults including the older population consider the lifestyle of families important to them, and 50.1% among the young people shared the same view [22].

The presence of epilepsy has been shown to strongly relate to low overall well-being and low self-esteem [4,23,24]. Affected persons may perceive themselves as unsuccessful, dependent, and handicapped. We propose that overprotective attitudes of families may strongly aggravate poor self-esteem which may lead to felt stigmatization even from young ages.

Studies showed that PWE are more likely to be socially dysfunctional than the general population [11,24,25]. Epilepsy can affect their ability to

Table 1
Respondents' demographics (n:330).

Demographic	Percentage (%)	
	PWE	GP (year of 2012)
<i>Gender</i>		
Female	64.8	49.8
Male	35.2	50.2
<i>Education</i>		
Primary school	54.5	47.48
High school	17.8	26.44
University	13.0	11.41
<i>Marital status</i>		
Married women	50.0	63.77
Married men	31.0	64.26
Unemployed	44.2	9.2

PWE: People with epilepsy, GP: General population.

The values for the national population belong to the year 2012, and the literature used for the national statistical rates are the following:

- 1- İstatistiklerle kadın, 2012. Turkish Statistical Institute. (<http://www.tuik.gov.tr/PreHaberBultenleri.do?id=13458>).
- 2- Statistics of Education Level, 2012. Address Based Population Registration System (ABPRS) Database. Turkish Statistical Institute. (http://www.turkstat.gov.tr/PreTablo.do?alt_id=1018).
- 3- Turkey in Statistics, 2012, Report of Turkish Statistical Institute, 2012. Publication number 3942. (<http://www.turkstat.gov.tr>).

Download English Version:

<https://daneshyari.com/en/article/6010809>

Download Persian Version:

<https://daneshyari.com/article/6010809>

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