



Attitudes towards people with epilepsy in Moscow

Alla Guekht^{a,b,*}, Anna Gersamiya^a, Igor Kaimovskiy^c, Maria Mizinova^b,
Alexander Yakovlev^d, Alexander Shpak^e

^a Moscow Research and Clinical Center for Neuropsychiatry of the Healthcare Department of Moscow, 43, Donskaya ul., Moscow 115419, Russian Federation

^b Department of Neurology, Neurosurgery and Medical Genetics, Pirogov Russian National Research Medical University, 8, Leninsky prospect, bL8, Moscow 119049, Russian Federation

^c V.M.Buyanov City Clinical Hospital, 26, Bakinskaya ul., 115516, Moscow, Russian Federation

^d Institute of Higher Nervous Activity and Neurophysiology of Russian Academy of Sciences, 5A Butlerova ul., 117485 Moscow, Russian Federation

^e The S. Fyodorov Eye Microsurgery Federal State Institution, 59A, Beskudnikovskiy Blvd., Moscow 127486, Russian Federation

ARTICLE INFO

Article history:

Received 25 December 2016

Revised 8 March 2017

Accepted 8 March 2017

Available online 18 April 2017

Keywords:

Epilepsy
Stigma
Understanding
Knowledge
Attitude

ABSTRACT

Purpose: To assess the knowledge and attitudes in Moscow towards people with epilepsy (PWE).

Methods: Data were collected from 1167 adults, permanent residents of Moscow, who were interviewed. A 10-item questionnaire was used addressing three major domains: familiarity with epilepsy (2 questions), understanding of epilepsy (5 questions), and attitude towards the PWE (3 questions). Results were standardized to the Moscow population.

Results: The study population was generally well informed about epilepsy. About 80% “has heard” of epilepsy; however, personal acquaintance with PWE was reported by less than half of the study participants. The level of understanding of the disease and its etiology was quite low. About 60% of the survey participants believed that epilepsy was a type of mental retardation. One-third (34%) of respondents were afraid to stay in the proximity of PWE. Only 38% of the survey participants considered epilepsy to be curable; men significantly less frequently than women. Overall, the level of understanding of epilepsy was proportional to the level of education of respondents.

Negative attitudes towards PWE were demonstrated in a significant part of the population. Almost half of the respondents would object to their child playing or studying with a child who has epilepsy and more than half (57%) were against the marriage of their daughter or son to a person with epilepsy. Two-fifths of the respondents ranked epilepsy as the “least preferred” of the six chronic diseases for a colleague.

Conclusion: This is the first study on awareness and attitudes to PWE in the adult population of Moscow. The study demonstrated that the general public is familiar with epilepsy, but has a rather low level of understanding of essential aspects of the disease. There is an overall high level of negative attitudes towards PWE in Russia, creating a need for targeted interventions. These results reinforced the importance of public education in reducing the stigma of epilepsy.

© 2017 Elsevier Inc. All rights reserved.

1. Introduction

Epilepsy carries a severe burden globally associated with a high degree of social stigma with a negative impact on quality of life (QOL) in people with epilepsy (PWE) [1–3], who experience many social, psychological, and economic consequences of stigma which are associated with poor QOL [4,5]. Previous studies by our group demonstrated lower QOL in PWE in Russia compared to several European countries [6,7].

Epilepsy-related stigma adds to psychological distress, deflated self-esteem and self-efficacy, lower QOL, and negative social and interpersonal experiences [8,9]. Epilepsy stigma has been considered to be

one of the most important factors that has a negative influence not only on PWE, but also on their families [2,10–12]. Although most PWE are fully functioning members of the society, adults with epilepsy have poorer social outcomes, including lower rates of marriage and higher rates of unemployment [13–15]. People with epilepsy are also more likely to live in households with lower income levels, be unemployed, or be unable to work [16]. Many individuals with epilepsy and their families report that stigma poses barriers to employment and leads to fear, embarrassment, and rejection by others, especially when seizures occur in public [17]. For the person with epilepsy, social disadvantages associated with epilepsy and co-occurring disorders such as depression may increase their perceptions of being stigmatized [18].

Attitude towards PWE has been investigated in many countries. The study done by Caveness in 1949 focused on issues related to the rights of PWE to marry, to be employed, and to be socially contacted. In 1951, the negative effects of stigma were identified as a serious problem for

* Corresponding author at: 43 Donskaya ul., Moscow 115419, Russian Federation.

E-mail addresses: guekht@mail.ru (A. Guekht), aanna187@gmail.com (A. Gersamiya), reanimator911@inbox.ru (I. Kaimovskiy), mizanova1985@yandex.ru (M. Mizinova), al_yakovlev@rambler.ru (A. Yakovlev), a_shpak@inbox.ru (A. Shpak).

PWE, with increased unemployment and social ostracism cited as top concerns [19]. Since then, similar studies were performed in various countries and regions, in selected populations (e.g., teachers, health care providers, students) [20,21], and in various languages. Generally, it is believed that measures to improve knowledge about epilepsy in the general public should ameliorate prejudices. More data are needed on the prevalence of stigma to develop appropriate measures. Studies on attitudes towards PWE have been carried out worldwide: in the United States [3,16,22], Italy [23,24], Denmark [25], Hungary [26], Czech Republic [27], Taiwan [28], Brazil [29,30], Croatia [31] and other countries. A substantial improvement in terms of attitude towards PWE has been demonstrated in the United States in the second half of the XXth century. There were no studies showing a similar trend in attitudes in other countries [32,33]. By contrast, deterioration of attitudes towards PWE was revealed in studies from Asia and Africa [34–38]. However, this important topic has not been adequately addressed in Russia.

The purpose of the study was to assess the level of knowledge and attitudes towards PWE in Moscow in three main domains. The first domain was familiarity with epilepsy, the second was understanding of epilepsy, and the third was attitudes towards PWE. We hypothesized that the level of knowledge and attitudes towards PWE would vary by gender, age, education, and marital status.

2. Methods

The study was done by face-to-face interviews of randomly selected adult healthy relatives and friends of patients with acute or chronic diseases, excluding epilepsy, admitted to V.M. Buyanov City Clinical Hospital (a convenience sample). This is one of the largest multidisciplinary hospitals in Moscow, where adult patients from all social groups and all districts of the city are treated. Accordingly, all segments of the population are represented among patient's relatives and friends. Study participants should have been adult permanent residents of Moscow, fluent in Russian, and willing to answer the questionnaire; there were no other selection criteria. Participants were enrolled successively twice a week, up to ten persons a day. The study population included 1167 people. Study participants were given a brief explanation of the purpose of the study, a guarantee of confidentiality, and were told that they could refuse to answer any questions. All the participants gave informed consent; they were not offered any compensation for their participation in the study. The study was approved by the Local Ethics Committee of the Moscow Research and Clinical Center for Neuropsychiatry of the Healthcare Department of Moscow.

2.1. The questionnaire

The level of knowledge and attitudes towards epilepsy were assessed using a 10-item questionnaire (modified from Caveness and Gallup [22], several questions not relevant for the Russian population were omitted).

The questionnaire addressed three major domains:

- Familiarity with epilepsy (Q1–Q2).
- Understanding of epilepsy (Q3–Q7).
- Attitude towards PWE (Q8–Q10).

The participants answered the questionnaire without any intervention by the interviewers but they were allowed to ask for clarifications regarding any of the questions.

2.2. Statistical analysis

Statistical analysis was performed using R software package version 3.2.3 (The R Foundation for Statistical Computing, <http://www.r-project.org>, accessed February, 12, 2016). Descriptive data are presented as absolute numbers (*n*) or/and percentages (%). The associations

between the responses and the demographic variables were examined with Fisher's exact test or Chi-squared test. In case of three or more groups, post-hoc pairwise comparisons were performed with *P* value adjustment for multiple comparisons by the Holm method. A probability value of less than 0.05 was considered significant.

2.3. Standardization procedures

The study population differed from the overall Moscow population. To adjust for the differences, direct standardization was performed. Data of the 2010 census counts for the city of Moscow [39] were used as a standard. All results were adjusted by age and, for questions 3–6 and 10, by gender. In questions with significant differences for education or marital status, when gender differences were not significant or relatively small, results were adjusted by age/education or age/marital status, respectively.

3. Results

Demographic characteristics of the study population (all Caucasians) are presented in Table 1. There were significant differences compared to the Moscow population [39], mostly in terms of age and marital status. The differences between study participants and the overall Moscow population were addressed by the standardization.

3.1. Familiarity with epilepsy (Q1–Q2)

The subjects were asked whether they had heard about epilepsy and whether they knew someone with epilepsy. Most of the respondents (81.5%; adjusted: 77.0%) had heard about epilepsy (Q1); the level of familiarity significantly increased with age of volunteers. Forty-eight percent of respondents (adjusted: 44%) knew somebody with epilepsy; significantly higher proportion among people above 65 y.o. and lower proportion in the age group 18–35 y.o.

Some associations with gender, education, and marital status were also revealed, but the magnitude of significant differences was about 10% (Table 2).

3.2. Understanding of epilepsy (Q3–Q7)

Twenty-four percent of respondents thought that epilepsy was a type of mental illness (Q3). About 60% of the survey participants believed that it was a type of mental retardation (Q7). Understanding of epilepsy as a type of mental retardation was significantly less

Table 1

Demographic characteristics of the study participants (*n* = 1167) and Moscow population.

Characteristic	Study population		Moscow population (%) [*]
	<i>n</i>	%	
Age			
18–35	175	15.0	34.8
36–50	344	29.5	27.0
51–65	396	33.9	22.7
66 and older	252	21.6	15.4
Sex			
Male	481	41.2	45.3
Female	686	58.8	54.7
Education			
Elementary school**	85	7.3	7.9
Secondary school	676	57.9	48.8
University	406	34.8	43.3
Marital status			
Unmarried/divorced	151	12.9	44.5
Married	1016	87.1	55.5

The differences in all demographic characteristics between study participants and Moscow population are significant (*P* < 0.000; for sex *P* = 0.005).

^{*} According to Moscow Census 2010 [39].

^{**} Including minimal and incomplete secondary education.

Download English Version:

<https://daneshyari.com/en/article/5628303>

Download Persian Version:

<https://daneshyari.com/article/5628303>

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