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# Knowledge, attitudes, and stigma towards epilepsy in different walks of life: A study in Georgia

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ABSTRACT

We conducted a survey to assess public awareness of epilepsy and stigma expression in different social groups in Tbilisi, Georgia. Respondents were divided into those from a medical or paramedical background, those with a nonmedical professional background, and a group with unskilled workers or unemployed individuals. One thousand and sixteen people completed a Knowledge, Attitude and Perception questionnaire. Medical and paramedical professionals had a better general knowledge about epilepsy, its possible causes, and its nature, but their views on treatment and attitudes towards epilepsy were the same or worse when compared to the other groups. Of the respondent, 14% would not let their children play with people with epilepsy, and 75% would not allow their children to marry a person with epilepsy. Nearly a third of teachers considered epilepsy a psychiatric disorder. This suggests a high degree of stigma towards epilepsy in Georgia. Increasing awareness is crucial to ameliorate this.



## 1. Introduction

Epilepsy is a chronic neurological disorder affecting at least 60 million people around the world with no age, racial, social, national, or geographic boundaries [1]. In developed countries, an average of 5 to 10 people for every 1000 individuals have epilepsy [2]. In Georgia, the prevalence rate of active epilepsy varies from 7 to 11 people per 1000 individuals; hence, around 35,000–40,000 people have active epilepsy [3]. It is known that people with epilepsy often experience stigma — a mark of infamy, disgrace, or reproach because of the condition. Because of this stigma, the social and personal expectations of people with epilepsy are often restricted, and this may affect their quality of life even more than the medical condition itself [4–7]. Worldwide, epilepsy is often associated with mental illness and cognitive disability, and this is also sometimes reflected in legislation which may impose restrictive rules and regulations on people with epilepsy [8]. As a result of this, people with epilepsy are more likely to be anxious and to suffer from low mood and low self-esteem. This also has a social impact as people with epilepsy have lower marriage rates and are more likely to be unemployed or underemployed than people in the general population [9–11]. Epilepsy-related stigma not only affects the person but also impacts on family and personal relationships [12–14]. Previous studies among people with epilepsy in Georgia suggested a decreased quality of life [15], but the level of stigma has not yet been investigated.

We attempted to ascertain factors that are likely to contribute to stigma towards people with epilepsy among people in different social groups in Tbilisi, the capital and largest city of Georgia. We ascertained general knowledge about epilepsy and seizure, beliefs about its etiology, and attitudes towards people with epilepsy in an urban setting.

## 2. Methods

We used a Georgian version of a questionnaire aimed at elucidating negative attitudes towards people with epilepsy. It was elaborated based on a Knowledge, Attitude, and Perception (KAP) questionnaire previously used [16] and further refined in China [17]. The questionnaire was translated into Georgian, taking cultural nuances into consideration. These were discussed in a cultural workshop, and an acceptable conceptual and linguistic equivalence was achieved. It was then subjected to an independent Georgian–English backwards

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translation and checked for gross inconsistencies or conceptual errors between the original source and the back-translated version. After testing of the prefinal variant, a final Georgian version of the questionnaire was agreed on. It consists of the following five main domains: general knowledge about epilepsy, possible causes of epilepsy, the nature of an epileptic seizure, views on the treatment of epilepsy, and attitude towards people with epilepsy.

We then conducted the survey between December 2009 and April 2010 in Tbilisi using the questionnaire. Face-to-face interviewing was chosen as the main method of data acquisition as it provided the opportunity to clarify any question when necessary. Most of the respondents recruited through direct approach in public locations were adults. To ensure the involvement of younger people, a random sample of students from the mailing list of four locally based higher education institutions were sent an electronic version of the questionnaire. They were asked to return the completed questionnaire by a deadline. All questionnaires were assessed for completeness. Participants were divided into three main groups according to their professional background: Group A — respondents with a medical or paramedical professional background (physicians, nurses, pharmacists, and medical students); Group B — respondents with a nonmedical professional background (teachers, state officials, and nonmedical students); and Group C — unskilled workers and unemployed people.

The study was approved by the National Council of Bioethics. No written consent was obtained as this was implicit in the participant agreeing to respond to the questionnaire, and this was agreed to by the Bioethics Council.

Statistical analysis was performed using SPSS (v17). Descriptive statistics were used to assess stigma expression among the different groups in the population. Pearson's chi-square statistics were used to find associations between variables. Two-sided probabilities of less than 0.05 were considered as statistically significant.

## 3. Results

A total of 975 people were approached face to face, and 209 (21%) of them refused to comply with the request to fill the questionnaire. A total of 361 higher education students were e-mailed the electronic version of the questionnaire, and 111 (31%) of them did not reply or complete it online. Therefore, 1016 persons provided data: 766 (75%) who agreed to a face-to-face interview and 250 (25%) who completed the online version. Women were predominant among the responders (69%), as males more often refused to participate. Mean age was 37 years (SD — 14 years); 10% had a medical background (Group A), 40% were unskilled workers or unemployed individuals (Group C), and the remaining 50% were other professionals (Group B). Table 1 provides the demographic characteristics of the participants.

**Table 1**
Demographic characteristics of the respondents.

| Characteristic | All (n = 1016) | Males (n = 314) | Females (n = 702) |
|---|---|---|---|
| | n (%) | n (%) | n (%) |
| *Education* | | | |
| None | 18 (1) | 6 (1) | 12 (2) |
| Incomplete secondary | 25 (3) | 2 (3) | 17 (2) |
| Secondary | 366 (36) | 128 (41) | 238 (34) |
| High (advanced) | 607 (60) | 171 (55) | 436 (62) |
| *Employment* | | | |
| Medical professionals (medical students, nurses, physicians) | 104 (10) | 14 (5) | 90 (13) |
| Nonmedical professionals (teachers, students, state officials, employers) | 510 (50) | 160 (51) | 350 (50) |
| Unskilled workers | 119 (11) | 42 (13) | 77 (11) |
| Unemployed | 283 (28) | 98 (31) | 185 (26) |
| *Residence* | | | |
| City | 910 (90) | 283 (90) | 627 (89) |
| Suburban/rural | 106 (10) | 31 (10) | 75 (11) |
| *Marital status* | | | |
| Single | 293 (29) | 113 (36) | 180 (26) |
| Married | 645 (64) | 183 (58) | 462 (66) |
| Divorced | 31 (3) | 9 (3) | 22 (3) |
| Widow/widower | 36 (4) | 5 (2) | 31 (4) |
| Separated | 11 (1) | 4 (1) | 7 (1) |

### 3.1. General knowledge

All responses are provided in Table 2. Most responders had some information about epilepsy (90%), but only 37% had seen a person having a seizure.

### 3.2. Possible causes and nature of epileptic seizures

In all groups, brain injury and heredity were considered as the major causes of epilepsy. Twenty percent of individuals in the medical group considered epilepsy as a psychiatric condition. Two hundred and two teachers (85% females) were interviewed, and about a third thought epilepsy to be a psychiatric disorder, and half of them considered epilepsy as hereditary.

### 3.3. Views on epilepsy treatment

Herbal medicine dispensed by traditional healers or as an alternative treatment for epilepsy was positively accepted equally by medical professionals (6%) and unskilled workers (5%), while nonmedical professionals found it less attractive (2%). A higher proportion of people in Group C (5%) suggested herbal medicine as a treatment of choice for epilepsy than in Group B (2%) (Pearson's chi-square (1, $N = 912$) $= 6.355$, $p = 0.012$).

Ten percent of respondents with a medical background considered epilepsy as an untreatable disease, while in the remaining groups, only 6% had this opinion (Table 2), but there was no statistically significant difference between groups.

### 3.4. Attitudes towards people with epilepsy

Only 14% of the respondents would object to their children befriending a person with epilepsy (similar data was found in all groups), while most of the responders (75%) would object to their offspring marrying a person with epilepsy (this was highest in people with a medical background — 82%, but this was not significant) (Table 3).

## 4. Discussion

This study provides some data about public awareness of epilepsy among people from different social groups in the capital of Georgia. Level of public awareness and perception of epilepsy vary in different cultures and societies. The acceptability of people with epilepsy in various societies has improved [16], but in spite of recent progress, epilepsy-related stigma still raises concerns.

Our results show considerably low awareness about epilepsy among people from different social groups. Attitudes towards people with epilepsy were also challenging and may lead to stigmatization.

Nearly three-quarters of respondents would not want their children marrying a person with epilepsy, and 14% would even object to them playing with a person with epilepsy. This is comparable to data from Western countries such as Italy and the United States [18].