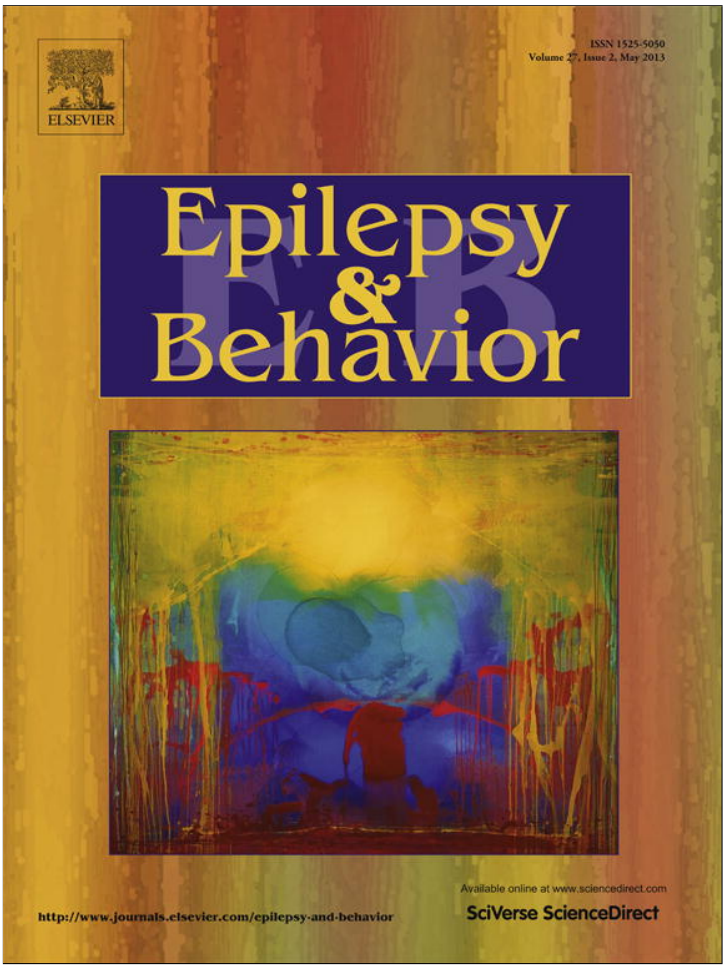

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Knowledge, attitudes, and stigma towards epilepsy in different walks of life: A study in Georgia

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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.

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.

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)

3.3. 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].

Table 2
Awareness of respondents on different medical aspects of epilepsy.

General information about epilepsy	All (n = 1016)	Medical professionals (n = 104)	Other professionals (n = 510)	Unskilled workers/ unemployed (n = 402)	p value
	n (%)	n (%)	n (%)	n (%)	
General knowledge					
Have you ever heard of, or read about, the disease called "epilepsy" or "convulsive seizures" (fits)? (answer: 'yes')	913 (90)	99 (95)	463 (91)	351 (87)	
Did you ever know anyone who had epilepsy? (answer: 'yes')	395 (39)	62 (60)	196 (38)	137 (34)	<0.001[a,b]
Have you ever seen anyone who was having a seizure? (answer: 'yes')	378 (37)	55 (53)	184 (36)	139 (35)	<0.001[a,b]
Possible causes and nature of epileptic seizures					
What do you think is the cause of epilepsy? (Multiple answers are allowed)					
Brain injury (traumatic injury or brain disorder other than stroke)	493 (49)	68 (65)	249 (49)	176 (44)	0.002[a] <0.001[b]
Hereditary disease	393 (39)	54 (52)	193 (38)	146 (37)	0.012[a] 0.004[b]
Birth trauma	112 (11)	23 (22)	53 (10)	36 (9)	<0.001[a,b]
Stress	118 (11)	18 (17)	56 (11)	44 (10)	
Stroke	80 (8)	10 (10)	28 (6)	42 (10)	0.005[c]
Other	18 (2)	2 (2)	8 (2)	8 (2)	
Don't know	289 (28)	14 (14)	144 (28)	131 (33)	0.003[a] <0.001[b]
What do you think an epileptic seizure is? (multiple answers are allowed)					
Convulsions	752 (74)	79 (76)	387 (76)	286 (71)	
Loss of consciousness	378 (37)	53 (51)	178 (35)	147 (37)	0.002[a] 0.007[b]
Transient changes of behavior	138 (14)	26 (25)	48 (9)	64 (16)	<0.001[a] 0.003[c] 0.03[b]
Period of amnesia	127 (13)	21 (20)	57 (11)	49 (12)	0.01[a] 0.04[b]
Don't know	100 (10)	2 (2)	42 (8)	56 (14)	0.02[a] 0.006[c] <0.001[b]
Views on treatment of people with epilepsy					
If your relatives or friends have epilepsy, what kind of treatment would you suggest? (multiple answers are allowed)					
Ask for a doctor	913 (90)	95 (96)	466 (95)	352 (94)	
Get medicine from drugstore by him/herself	10 (1)	–	6 (1)	4 (1)	
Ask for a herbal medicine doctor	36 (4)	6 (6)	10 (2)	20 (5)	0.012[c]
Acupuncture	15 (2)	2 (2)	5 (1)	8 (2)	
Surgical treatment	33 (3)	3 (3)	18 (4)	12 (3)	
Ask for God's help	272 (27)	29 (29)	146 (30)	97 (26)	
Accept that "epilepsy is untreatable"	67 (7)	10 (10)	33 (7)	24 (6)	
No need to treat	7 (1)	–	2 (0)	5 (1)	
Don't know what to recommend	26 (3)	1 (1)	15 (3)	10 (3)	

[a] Significant difference between Groups A (medical professionals) and B (other professionals).
[b] Significant difference between Groups A (medical professionals) and C (unskilled workers/unemployed).
[c] Significant difference between Groups B (other professionals) and C (unskilled workers/unemployed).

Twenty percent of respondents considered epilepsy as a psychiatric disorder. This is different from results from Hong Kong and Taiwan, where 10% and 7% of respondents, respectively, believed that epilepsy is a form of mental illness [19,20], and is closer to data from China [17] and Greece [21], where around 15% of respondents consider epilepsy as a form of psychiatric disorder.

Health care professionals are considered as the main opinion makers on health-related issues in the general population. There are

Table 3
Attitudes and misconceptions towards people with epilepsy.

Attitudes towards people with epilepsy	All (n = 1016)	Medical professionals (n = 104)	Other professionals (n = 510)	Unskilled workers/unemployed (n = 402)
	n (%)	n (%)	n (%)	n (%)
Would you object to any of your children in school or at play associating with people who sometimes had seizures (fits)? (answer: 'yes')	145 (14)	13 (13)	70 (14)	62 (15)
Would you object to your son or daughter marrying a person who sometimes had seizures (fits)? (answer: 'yes')	757 (75)	85 (82)	378 (74)	294 (73)
Do you think people with epilepsy should be employed in jobs the same as other people? (answer: 'yes')	811 (80)	84 (81)	410 (80)	17 (80)
Do you think epilepsy is a form of insanity or not? (answer: 'yes')	206 (20)	27 (26)	100 (20)	79 (20)

few data describing epilepsy perception among health care workers or medical students. In our study, respondents with a medical background showed a relatively high level of prejudice and misconceptions when compared to the other groups. In some cases, attitudes towards epilepsy among medical professionals are more stigmatizing than those of the other groups, which could be a major source of epilepsy-related stigma in Georgia. Part of this could be the inadequate coverage of epilepsy in the curriculum of Georgian medical schools. The inclusion of comprehensive information about epilepsy in the curriculum of health care professionals could ameliorate this.

Teachers' views are important for the development of perceptions and awareness in the younger generations. About one-third of teachers consider epilepsy a genetic disease, and half of them consider it a psychiatric disorder. Results from a US study suggest that about 30% of teachers may have negative attitudes towards epilepsy [22]. Awareness training for teachers may, therefore, also help to reduce stigma and misconceptions.

5. Limitations

There are some potential limitations to the present study. It was carried out in an urban population in a major city. The results cannot be extrapolated nationally as there are considerable cultural differences between urban and rural areas. The use of two distinct methodologies, face-to-face interview using the questionnaire and an electronic version, may have also have introduced bias. Indeed, there is the possibility of face-to-face responders providing more 'politically correct' answers to some sensitive questions, and this may introduce bias. Another potential source of bias is the preponderance of women among responders. The results, therefore, should be considered as a minimum estimation of the problem as the potential bias may have led to underestimations.

6. Conclusion

In conclusion, there seems to be a high degree of stigma in relation to epilepsy in Georgia. More actions are needed to increase its awareness among the general population. The high levels of prejudice and misconceptions among health care professionals are of special concern. Concerted actions are required to increase public awareness and to increase acceptability of people with epilepsy.

Conflict of interest

None of the authors has any conflict of interest to disclose in relation to this work.

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References

[1] Ngugi AK, Bottomley C, Kleinschmidt I, Sander JW, Newton CR. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. Epilepsia 2010;51:883–90.
[2] Sander JW. The epidemiology of the epilepsies revisited. Curr Opin Neurol 2003;16:165–70.
[3] Lomidze G, Kasradze S, Kvernadze D. The prevalence and treatment gap of epilepsy in Tbilisi, Georgia. Epilepsy Res 2012;98:123–9.
[4] Reno BA, Fernandes PT, Bell GS, Sander JW, Li LM. Stigma and attitudes on epilepsy: a study with secondary school students. Arq Neuropsiquiatr 2007;65:49–54.
[5] de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. Epilepsy Behav 2008;12:540–6.
[6] Baker GA. The psychosocial burden of epilepsy. Epilepsia 2002;43:26–30.
[7] Jacoby A, Austin JK. Social stigma for adults and children with epilepsy. Epilepsia 2007;48:6–9.
[8] Villanueva-Gomez F. Epilepsy, society and rights. Rev Neurol 1998;26:294–7.
[9] Placencia M, Farmer PJ, Jumbo L, Sander JW, Shorvon SD. Levels of stigmatization of patients with previously untreated epilepsy in northern Ecuador. Neuroepidemiology 1995;14:147–54.
[10] Collings JA. Psychosocial well-being and epilepsy: an empirical study. Epilepsia 1990;31:418–26.
[11] Hermann BP, Whitman S, Wyler AR, Anton MT, Vanderzwagg R. Psychosocial predictors of psychopathology in epilepsy. Brit J Psychiatry 1990;156:98–105.
[12] Westbrook LE, Bauman LJ, Shinnar S. Applying stigma theory to epilepsy: test of a conceptual model. J Pediatr Psychol 1992;1S:633–49.
[13] Baker GA, Brooks J, Buck D, Jacoby A. The stigma of epilepsy: a European perspective. Epilepsia 2000;41:98–104.
[14] Lim HW, Song HS, Hwang YH, et al. Predictors of suicidal ideation in people with epilepsy living in Korea. J Clin Neurol 2010;6:81–8.
[15] Djibuti M, Shakarishvili R. Influence of clinical, demographic, and socioeconomic variables on quality of life in patients with epilepsy: findings from Georgian study. J Neurol Neurosurg Psychiatry 2003;74:570–3.
[16] Caveness WF, Gallup GH. A survey of public attitudes toward epilepsy in 1979 with an indication of trends over the past thirty years. Epilepsia 1980;21:509–18.
[17] Lai CW, Huang X, Lai YHC, Zhang Z, Liu G, Yang MZ. Survey of public awareness, understanding, and attitudes toward epilepsy in Henan province, China. Epilepsia 1990;31:182–7.
[18] Canger R, Cornaggia C. Public attitudes toward epilepsy in Italy: results of a survey and comparison with U.S.A. and West German data. Epilepsia 1985;26:221–6.
[19] Fong CY, Hung A. Public awareness, attitude and understanding of epilepsy in Hong Kong special administrative region, China. Epilepsia 2002;43:311–6.
[20] Chung MY, Chang YC, Lai YHC, Lai CW. Survey of public awareness, understanding, and attitudes toward epilepsy in Taiwan. Epilepsia 1995;36:488–93.
[21] Diamantopoulos N, Kaleyias J, Tzoufi M, Kotsalis C. A survey of public awareness, understanding, and attitudes toward epilepsy in Greece. Epilepsia 2006;47:2154–64.
[22] Bishop M, Slevin B. Teachers' attitudes toward students with epilepsy: results of a survey of elementary and middle school teachers. Epilepsy Behav 2004;5:308–15.