Validation of the Georgian Version of a Stigma Scale of Epilepsy

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Abstract

Introduction: Stigma Scale of Epilepsy (SSE), initially developed in Brazil, is accepted worldwide as a sensitive tool for assessing epilepsy-related stigma. We adapted and validated a Georgian version of SSE.

Materials and methods: The SSE originated in Brazil and was translated into Georgian by three independent experts through forward and backward translation. The final version was generated for validation after handling gross or conceptual inconsistencies between the source and the new format.

We used Cronbach's alpha to assess the internal consistency of the Georgian version of SSE. To explore the construct of SSE subscales in the Georgian version, we used principal components and factor analysis. Varimax rotation was applied. The Kaiser-Meyer-Olkin Measure and Bartlett's test of sphericity were employed to assess the sampling adequacy. A probability < 0.05 was considered statistically significant.

Results: 87 adults, 32 (37%) with epilepsy and 55 (63%) without epilepsy were enrolled. The overall mean score of SSE was 19.5 (SD 10.1; min. 2, max. 53), and the differences between people with [20.7 (SD 8.9; min. 2, max. 53)] and without epilepsy [17.5 (SD 10.4; min. 3, max. 42)] were not statistically significant. Cronbach's alpha for the overall sample was 0.854; for the epilepsy cohort it was 0.876, and for individuals without epilepsy 0.823, indicating good SSE internal consistency. Kaiser-Meyer-Olkin Measure was 0.705 and Bartlett's test of sphericity was 926.2 (df 276; $p<0.001$), suggesting acceptable sample adequacy.

Discussion: The Georgian version of the SSE is a valid and reliable measurement tool for assessing epilepsy-related stigma determinants among the country's population.

Key-words: Epilepsy-related stigma, assessment tool, reliability, validity

1. Introduction

Epilepsy impacts at least 50 million individuals worldwide regardless of age, race, social class, nationality, or geographic location [1]. Epidemiological data suggest that in Georgia, active epilepsy affects about 35,000 individuals living with epilepsy across the country [2].

Epilepsy poses a significant public health challenge everywhere but with a more pronounced impact on low and middle-income countries where most people with epilepsy live [3]. It is compounded by many psychiatric, somatic and psychosocial comorbidities and places a substantial economic burden on healthcare systems. Seizures may lead to functional impairment, accidents, injuries, and premature mortality [4]. Complications associated with epilepsy include status epilepticus and sudden unexpected death (SUDEP), both impacting the risk of premature mortality [5,6].

Neuropsychiatric comorbidities such as mood and anxiety disorders are frequent in people with epilepsy and correlate with the stigma associated with epilepsy, which often has a more severe impact on individuals than seizures [7]. Stigma mainly results from misconceptions and negative attitudes regarding epilepsy in society, significantly influencing the quality of life for individuals with epilepsy and their families [8,9].

The social stigma resulting from epilepsy creates obstacles to successful integration into society, obtaining a comprehensive education, establishing a family, or securing employment. Consequently, stigma in epilepsy is a central contributor to health inequalities [10].

Since stigma represents a potential risk factor for physical and mental health problems and varies in degree and perception across different populations [11], developing a good screening tool tailored to specific populations to measure stigma comprehensively is crucial. This enables the planning and implementation of appropriate healthcare interventions to address and manage epilepsy-related stigma and improve health outcomes within a particular society.

Various scales have been developed to measure the level of stigma among different population segments [12–14], but none of these options has been validated in Georgia. The consistency, psychometric properties, and cultural validity of these scales have not been assessed, and the current level of epilepsy-related stigma within the population of Georgia remains unknown.

Georgia is an upper-middle-income country [15] with a population of 3 736 400 people, located in western Europe and central Asia. The capital city is Tbilisi, where about a third of the population lives [16]. The mainstay of epilepsy care in Georgia is provided by a state program for early diagnosis and prevention of epilepsy, allowing initial consultations and EEG investigation free of charge. Stigma level towards epilepsy seems to be problematic. A 2013 study suggested considerable stigmatisation in the population, including those with a medical education background [17], mainly regarding marriage, interpersonal relationships, and the perception of epilepsy as a form of insanity.

The current study aimed to develop and validate a tool in the Georgian language for conducting population studies, specifically focusing on investigating epilepsy-related stigma. For this, we considered the questionnaire Stigma Scale of Epilepsy, developed and validated in Brazil, the most appropriate.

2. Material and methods

2.1 Study Questionnaire

For validation purposes, the "Stigma Scale of Epilepsy" (SSE), a widely used scale initially developed in Brazil, was selected as it effectively captures the emotional reactions towards epilepsy in individuals without the condition [14].

The SSE comprises five questions and 24 sub-items assessing social stigma:

- The first item comprises a single question that provides information on r the general understanding of condition.
- The second item consists of four questions that evaluate respondents' emotions when witnessing an epileptic seizure.
- The third and fourth items comprise seven questions each and assess respondents' perspectives on the challenges in daily life and perceptions associated with epilepsy from the point of view of a person with epilepsy.
- The fifth domain comprises five questions and gathers information about predisposition and discrimination associated with epilepsy.

For each item in the SSE, respondents are required to indicate one of four alternatives corresponding to their level of agreement: "Not at all," "A little," "A lot," and "Totally."

2.2 Translation and adaptation of the SSE

SSE was translated into Georgian by three independent bilingual specialists without medical knowledge. Following the translation process, the specialists exchanged their translated versions. After careful verification, a preliminary Georgian version was established, which was then reviewed and corrected by neurologists and psychologists to ensure the highest quality. Subsequently, three independent specialists translated the updated version into English. The translated English version was then compared to the original SSE to assess its accuracy. After this, a pre-final version of the Georgian SSE was produced. This pre-final version was then distributed among 17 Georgian speakers without a medical background. Any misunderstanding or ambiguity regarding the questions was addressed, with neurologists and neuropsychologists refining the questions. As a result, the final Georgian version of the SSE questionnaire was accepted (see Supplement 1).

Supplement 1. Georgian Version of the Stigma Scale of Epilepsy

2.3 Sample Size

The study sample comprised people attending the Institute of Neurology and Neuropsychology (INN), Tbilisi, Georgia. A total of 32 individuals with epilepsy and 55 individuals without were included. The sample size was based on the original research parameters, where 80 participants were selected from the general population and people with epilepsy.

2.4 Ethics Statement

The Ethics Committee of the INN (INN-004/2023) approved the project proposal. The study followed the principles outlined in the WMA Declaration of Helsinki.

2.5 Study participants

Georgian-speaking individuals from the community without epilepsy, aged 18-60 years and residing in Tbilisi, were approached between 01 Feb. and 01 Mar. 2023; Twelve participants were randomly selected from fourth-year students at Caucasus International University (CIU) using systematic sampling from a pool of 175 students from medical and non-medical faculties. The remaining 43 individuals without epilepsy were randomly chosen from a group of 50 representatives of the general population through outdoor interviews. Questionnaires were also given to 34 consecutive people with epilepsy who had sought treatment at the INN during the same period. Individuals with significant mental or cognitive abnormalities were excluded from the study.

The study participants completed the questionnaires with explicit instructions regarding selecting the category they deemed most suitable for each item (See Fig. 1).

Figure 1. Participant flow chart

Sociodemographic information, including age, gender, marital status, and educational level, was recorded. For those with epilepsy, additional information such as a family history of epilepsy, duration, type of seizures, and antiseizure medication (ASM) treatment was recorded.

2.6 Statistical analysis

Descriptive statistics were used to analyse the demographic variables. The normality of the distribution for continuous variables was assessed using the Kolmogorov-Smirnov and Shapiro-Wilk tests. The Mann-Whitney U test was employed to identify differences between independent non-parametric variables. Cronbach's alpha was computed to evaluate reliability.

The coding of the first SSE question exhibits an inverted hierarchy compared to all other questions. Specifically, a lower score on the first question implies greater stigmatisation, while lower scores on all other questions indicate reduced stigma. This discrepancy can potentially impact the accuracy of Cronbach's alpha coefficient assessment. To address this, we recorded the categories of the first question in the opposite order and conducted an additional evaluation of internal consistency.

A principal components and confirmatory factor analysis were performed to explore the construct of SSE subscales in the Georgian version. Varimax rotation was applied. The Kaiser-Meyer-Olkin Measure and Bartlett's test of sphericity were employed to assess the sampling adequacy. Scree plots were constructed to determine the number of factors for the questionnaire. A significance level of $p < 0.05$ was considered statistically significant. All statistical analyses were performed using IBM SPSS Statistics for Windows, Version 23.0 (Armonk, NY: IBM Corp), AMOS 23 was used for confirmatory factor analysis.

3. Results

Eighty-seven people were enrolled, of whom 32 (37%) had epilepsy. For more details, see Table 2.

Table 2. Demographic and clinical characteristics of the 87 individuals

	No epilepsy; n=55	*Epilepsy; n=32*
Sex		
Female	33 (60%)	20 (62.5%)
Male	22 (40%)	12 (37.5%)
Age		
Mean (SD)	32.31 (14.26)	34.31 (17.41)
Median (IQR)	26 (23, 40)	28.5 (21, 40)
Age at seizure onset		
Mean (SD)	N/A	18.53 (11.53)
Median (IQR)	N/A	17 (13, 22)
Age at diagnosis		
Mean (SD)	N/A	19.69 (11.18)

Median (IQR)	N/A	18 (13.25, 23.5)
Religion		
No	3 (5.45%)	1 (3.13%)
Orthodox Cristian	50 (90.91%)	31 (96.88%)
Muslim	2 (3.64%)	0
Education		
Primary school	1 (1.82%)	1 (3.13%)
Secondary school	3 (5.45%)	9 (28.13%)
Vocational non-medical education (college)	9 (16.36%)	4 (12.5%)
Student	12 (21.82%)	9 (28.13%)
Medical Faculty	7 (12.73%)	1 (3.13%)
Non-medical Faculty	5 (9.09%)	8 (14.55%)
University Graduate	30 (54.55%)	9 (28.13%)
Medical Faculty	10 (18.18%)	0
Non-medical Faculty	20 (36.36%)	9 (28.13%)
ASM (yes)	0	32 (100%)
Seizure type		
Focal with/without impaired awareness	N/A	17 (53.13%)
Focal to bilateral tonic clonic seizure	N/A	6 (18.75%)
Generalised	N/A	9 (28.13%)

ASM – anti-seizure medication

Descriptive data on the distribution of preferred answers on different domains of the SSE for individuals with and without epilepsy are provided in Table 3.

Table 3. Distribution of answers to SSE questions from 55 individuals without epilepsy and 32 people with epilepsy

	No epilepsy				***Epilepsy***			
	Not at al	**A little**	**A lot**	**Totally**	**Not at all**	**A little**	**A lot**	**Totally**
1. Do you think that people with epilepsy feel able to control their own epilepsy?								
	26 (47.27%)	21 (38.18%)	2 (3.64%)	6 (10.91%)	13 (40.63%)	8 (25%)	6 (18.75%)	5 (15.63%)
2. How would you feel when you see an epileptic seizure?								
2.1. Scared	34 (61.82%)	6 (10.91%)	11 (20%)	4 (7.27%)	19 (59.38%)	7 (21.88%)	4 (12.5%)	2 (6.25%)
2.2. Fear	26 (47.27%)	15 (27.27%)	7 (12.73%)	7 (12.73%)	19 (59.38%)	6 (18.75%)	2 (6.25%)	5 (15.63%)
2.3. Sadness	20 (36.36%)	12 (21.82%)	13 (23.64%)	10 (18.18%)	6 (18.75%)	6 (18.75%)	9 (28.13%)	11 (34.38%)
2.4. Pity	22 (40%)	18 (32.73%)	5 (9.09%)	10 (18.18%)	12 (37.5%)	8 (25%)	3 (9.38%)	9 (28.13%)
3. Which difficulties do you think people with epilepsy have in their daily lives?								
3.1. Relationships	22 (40%)	26 (47.27%)	7 (12.73%)	0	21 (65.63%)	7 (21.88%)	1 (3.13%)	3 (9.38%)
3.2. Work	18 (32.73%)	24 (43.64%)	7 (12.73%)	6 (10.91%)	17 (53.13%)	9 (28.13%)	2 (6.25%)	4 (12.5%)
3.3. School	34 (61.82%)	17 (30.91%)	2 (3.64%)	2 (3.64%)	18 (56.25%)	8 (25%)	4 (12.5%)	2 (6.25%)

3.4. Friendships	42 (76.36%)	9 (16.36%)	2 (3.64%)	2 (3.64%)	23 (71.88%)	5 (15.63%)	4 (12.5%)	0
3.5. Sexual	31 (56.36%)	18 (32.73%)	4 (7.27%)	2 (3.64%)	23 (71.88%)	6 (18.75%)	2 (6.25%)	1 (3.13%)
3.6. Emotional	10 (18.18%)	24 (43.64%)	15 (27.27%)	6 (10.91%)	10 (31.25%)	10 (31.25%)	7 (21.88%)	5 (15.63%)
3.7. Prejudice	20 (36.36%)	13 (23.64%)	12 (21.82%)	10 (18.18%)	17 (53.13%)	7 (21.88%)	7 (21.88%)	1 (3.13%)
4. How do you think that people with epilepsy feel?								
4.1. Worried	7 (12.73%)	23 (41.82%)	19 (34.55%)	6 (10.91%)	12 (37.5%)	10 (31.25%)	5 (15.63%)	5 (15.63%)
4.2. Dependent	13 (23.64%)	18 (32.73%)	19 (34.55%)	5 (9.09%)	16 (50%)	6 (18.75%)	5 (15.63%)	5 (15.63%)
4.3. Incapable	22 (40%)	22 (40%)	9 (16.36%)	2 (3.64%)	22 (68.75%)	7 (21.88%)	1 (3.13%)	2 (6.25%)
4.4. Fearful	35 (63.64%)	13 (23.64%)	4 (7.27%)	3 (5.45%)	26 (81.25%)	3 (9.38%)	3 (9.38%)	0
4.5. Depressed	10 (18.18%)	21 (38.18%)	17 (30.91%)	7 (12.73%)	11 (34.38%)	12 (37.5%)	3 (9.38%)	6 (18.75%)
4.6. Ashamed	22 (40%)	22 (40%)	9 (16.36%)	2 (3.64%)	20 (62.5%)	8 (25%)	3 (9.38%)	1 (3.13%)
4.7. The same as those without epilepsy	31 (56.36%)	11 (20%)	8 (14.55%)	5 (9.09%)	9 (28.13%)	9 (28.13%)	6 (18.75%)	8 (25%)
5. In your opinion, the prejudice in epilepsy will be related to?								
5.1. Relationships	29 (52.73%)	17 (30.91%)	7 (12.73%)	2 (3.64%)	27 (84.38%)	3 (9.38%)	2 (6.25%)	0
5.2. Marriage	38 (69.09%)	12 (21.82%)	5 (9.09%)	0	28 (87.5%)	2 (6.25%)	1 (3.13%)	1 (3.13%)
5.3. Work	24 (43.64%)	22 (40%)	6 (10.91%)	3 (5.45%)	27 (84.38%)	2 (6.25%)	2 (6.25%)	1 (3.13%)
5.4. School	26 (47.27%)	16 (29.09%)	9 (16.36%)	4 (7.27%)	25 (78.13%)	3 (9.38%)	4 (12.5%)	0
5.5. Family	33 (60%)	17 (30.91%)	4 (7.27%)	1 (1.82%)	27 (84.38%)	4 (12.5%)	1 (3.13%)	0

The overall mean SSE score was 43.5 (SD 10.1; min. 2, max. 77). Among individuals without epilepsy, the mean SSE score was 47.6 (SD 10.1; min. 26, max. 77), while for those with epilepsy, it was 42.5 (SD 11.2; min. 27, max. 68). The difference between groups was not statistically significant.

Summed scores 30 or less (5th percentile) were seen in 4.6% of respondents, and 64 or more (95th percentile) was scored by 3.4 %, indicating that the questionnaire has no problematic floor/ceiling effect.

3.1 Reliability and validity

Cronbach's alpha for the overall sample was 0.854. For the epilepsy cohort, it was 0.876; for individuals without epilepsy, it was 0.823, suggesting good internal consistency.

3.2 Principal component analysis

For the principal component analysis, the Kaiser-Meyer-Olkin Measure was found to be 0.705, while Bartlett's test of sphericity yielded 926.2 (df 276; p<0.001), indicating acceptable sample adequacy. The principal component extraction, based on eigenvalues of less than one, resulted in eight components that explained 71.7% of the total variance. Alternatively, when extraction was based on six components, the variance explained was 62.9% (with the lowest eigenvalue being 1.162) (see Fig.2).

Figure 2. The scree plot of SSE components for all 87 study participants

Table 4 displays the results of the rotated component matrix of principal components and factor analysis. The bold and underlined data indicate that the corresponding item has a factor loading >0.5, which suggests that the item is strongly associated with that specific component, except for the first and 4.7 questions, where the maximum factor load is 0.204 and 0.254.

Table 4. Rotated component matrix and item distribution through six components

	Components					
	1	**2**	**3**	**4**	**5**	**6**
1. Do you think that people with epilepsy feel able to control their own epilepsy?						
	-.144	.053	**.204**	-.745	.046	-.087
2. How would you feel when you see an epileptic seizure?						
2.1. Scared	.161	.227	.071	.100	.019	**.719**
2.2. Fear	.051	**.725**	.062	.077	.019	.304
2.3. Sadness	.263	**.523**	-.474	.196	-.006	-.040
2.4. Pity	.317	**.553**	-.321	-.073	.054	.200
3. Which difficulties do you think people with epilepsy have in their daily lives?						
3.1. Relationships	**.588**	.144	.171	.154	.068	-.011
3.2. Work	**.678**	.269	.189	-.005	.133	-.014
3.3. School	**.655**	.046	-.080	.022	.138	.139
3.4. Friendships	**.836**	-.024	.078	.165	.073	-.051
3.5. Sexual	**.747**	.168	.106	.150	-.131	.038
3.6. Emotional	.386	.356	-.028	**.573**	-.176	-.305
3.7. Prejudice	.233	.110	.171	.120	.**361**	-.454
4. How do you think that people with epilepsy feel?						
4.1. Worried	.120	.275	.203	.366	**.502**	-.036
4.2. Dependent	.136	**.783**	.155	.075	-.033	-.177
4.3. Incapable	.086	**.766**	.255	.034	.269	.092
4.4. Fearful	.246	**.423**	.002	.312	.415	.342
4.5. Depressed	.151	.470	.049	**.662**	.131	-.146
4.6. Ashamed	.368	.142	.162	.287	**.561**	-.126
4.7. The same as those without epilepsy	.088	.068	-.134	.**254**	-.801	-.026
5. In your opinion, the prejudice in epilepsy will be related to?						
5.1. Relationships	.025	.049	**.552**	.431	.299	.334
5.2. Marriage	.074	-.055	.382	**.602**	.123	.253
5.3. Work	.311	.192	**.590**	.211	.387	.099
5.4. School	.164	.140	**.820**	-.020	.247	-.084
5.5. Family	.153	.037	**.796**	-.072	-.010	-.041

Bold and underlined measurers represents factor loading based on Pearsons' correlation coefficient between items and components;

3.3. Confirmatory Factor analysis (CFA)

A model fit estimation for CFA showed the following results: The root mean square error of approximation (RMSEA) was 0.108; Goodness of fit index (GFI) = 0.715; Baseline comparisons were as follows: normed fit index (NFI) = 0.543, IFI (incremental fit index) = 0.705, Tucker–Lewis index (TLI) = 0.638, comparative fit index (CFI) = 0.689. When the questionnaire construct is ideal, all those parameters should be more than 0.9. In our case parameters, especially NFI are lower, indicating that the six-factor construct of the scale needs further refinement.

The first component comprises most items from the third question and represents underlying daily difficulties in interpersonal relationships for people with epilepsy. Items 3.6 and 3.7 were allocated in the 4th and 5th components together with those questions, which more characterise emotional and prejudice towards people with epilepsy. Most of the items from the second and fourth questions were comprised in the second component, describing fear, anxiety, and concern when witnessing an epileptic attack or what people with epilepsy feel. The third component comprises most items from the fifth question focused on factors related to prejudice in epilepsy.

The CFA chart showed that components have mild to moderate correlations between each other (from 0,36 to 0.75). Conversely, the correlation between components and most items is within the range of 0.6 to 0.9. However, items one and 4.7 have a weak correlation with their components (0.04 and -0.08), which can compromise the reliability of SSE.

4. Discussion

Overcoming the stigma associated with epilepsy poses a significant challenge, as it encompasses various social components and entails psychological issues such as diminished self-esteem, fear, anxiety, and depression. People with epilepsy may also face social difficulties, including driving restrictions, unemployment, and social isolation [18,19].

Multiple studies have demonstrated that higher levels of perceived stigma are strongly associated with lower quality of life and negatively correlated with quality of life scores [20,21]. Effectively addressing epilepsy stigma necessitates evaluating and analysing reliable data, which can only be reached through validated scales.

We adapted and validated the Georgian version of the Stigma Scale of Epilepsy. Reliability analysis showed good internal consistency of the Georgian version of the SSE. The principal component analysis demonstrated acceptable discriminant validity in each domain. Our findings are consistent with the Brazilian and Chinese scale versions, where the internal consistency parameters [14,22] and discriminant ability [22] were found to be satisfactory.

However, there were problems with questions 1 and 4.7. shoving less consistency into the overall construct of the questionnaire. The same was observed in terms of the first question during the reliability analysis of the Chinese version of the SSE [22]. This could be due to inverse coding of the question, as well as some problems in the formulation and/or understanding of the question content. The same problems carry item 4.7 in the Georgian version of the SSE; Those two questions showed also less loading factor values during the principal component, as well as CFA analysis. Both questions need further refinement that can be done during the implementation of the SSE in routine research practice.

4.1 Limitations

The study has some limitations. One such limitation is the relatively small sample size, which may engender questions regarding the study's statistical power. However, it is noteworthy that the sample size aligns closely with the original Brazilian study. Furthermore, study participants were identified through random street interviews, encompassing students with and without medical backgrounds and examining individuals with epilepsy. This comprehensive approach contributes to the enhanced representativeness of our sample, rendering it more reflective of the broader population.

Confirmatory factor analysis suggested several issues with the questionnaire. Primarily, the model fit comparisons indicate values that do not align with the ideal range. This observation underscores the need for additional refinement of the Georgian version of the SSE, explicitly addressing the formulation of questions that exhibit the most significant challenges concerning factor loading, precisely questions 1 and 4.7. We anticipate further data collection will allow us to refine these questions. Additional data will also enable the reassessment of the internal consistency and CFA parameters, aiming to enhance the overall performance of the SSE.

4.2 Conclusion

We demonstrated that the Georgian version of the SSE is a valid and reliable measurement tool for assessing epilepsy-related stigma among the country's population.

Author Contributions

SK, NG, and GL contributed substantially to the conception or design of the work, acquisition of data, drafting of the manuscript for content, and interpretation of data. JWS contributed to the study design and manuscript revision. NG and ML were involved in data collection and database preparation for statistical analyses. GL conducted data analysis and interpretation. Each author played a role in drafting and critically revising the work for important intellectual content. All authors gave their final approval of the version to be published.

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References

[1] Epilepsy n.d. https://www.who.int/news-room/fact-sheets/detail/epilepsy (accessed July 16, 2023).

[2] Lomidze G, Kasradze S, Kvernadze D, Okujava N, Toidze O, De Boer HM, et al. The prevalence and treatment gap of epilepsy in Tbilisi, Georgia. Epilepsy Research 2012;98:123–9. https://doi.org/10.1016/j.eplepsyres.2011.08.021.

[3] Ngugi AK, Bottomley C, Kleinschmidt I, Sander JW, Newton CR. Estimation of the burden of active and life-time epilepsy: A meta-analytic approach: Estimation of the Burden of Epilepsy. Epilepsia 2010;51:883–90. https://doi.org/10.1111/j.1528-1167.2009.02481.x.

[4] Mariotti S, Valentin D, Ertan D, Maillard L, Tarrada A, Chrusciel J, et al. Past Trauma Is Associated With a Higher Risk of Experiencing an Epileptic Seizure as Traumatic in Patients With Pharmacoresistant Focal Epilepsy. Front Neurol 2021;12:669411. https://doi.org/10.3389/fneur.2021.669411.

[5] Lowerison MW, Josephson CB, Jetté N, Sajobi TT, Patten S, Williamson T, et al. Association of Levels of Specialized Care With Risk of Premature Mortality in Patients With Epilepsy. JAMA Neurol 2019;76:1352. https://doi.org/10.1001/jamaneurol.2019.2268.

[6] O'Neal TB, Shrestha S, Singh H, Osagie I, Ben-Okafor K, Cornett EM, et al. Sudden Unexpected Death in Epilepsy. Neurology International 2022;14:600–13. https://doi.org/10.3390/neurolint14030048.

[7] Tombini M, Assenza G, Quintiliani L, Ricci L, Lanzone J, Ulivi M, et al. Depressive symptoms and difficulties in emotion regulation in adult patients with epilepsy: Association

with quality of life and stigma. Epilepsy Behav 2020;107:107073. https://doi.org/10.1016/j.yebeh.2020.107073.

[8] Shi Y, Wang S, Ying J, Zhang M, Liu P, Zhang H, et al. Correlates of perceived stigma for people living with epilepsy: A meta-analysis. Epilepsy Behav 2017;70:198–203. https://doi.org/10.1016/j.yebeh.2017.02.022.

[9] Hohmann L, Berger J, Kastell S-U, Holtkamp M. Perceived epilepsy-related stigma is linked to the socioeconomic status of the residence. Front Public Health 2022;10:952585. https://doi.org/10.3389/fpubh.2022.952585.

[10] Andersson K, Ozanne A, Zelano J, Malmgren K, Chaplin JE. Perceived stigma in adults with epilepsy in Sweden and associations with country of birth, socioeconomic status, and mental health. Epilepsy Behav 2022;136:108886. https://doi.org/10.1016/j.yebeh.2022.108886.

[11] Kwon C, Jacoby A, Ali A, Austin J, Birbeck GL, Braga P, et al. Systematic review of frequency of felt and enacted stigma in epilepsy and determining factors and attitudes toward persons living with epilepsy—Report from the International League Against Epilepsy Task Force on Stigma in Epilepsy. Epilepsia 2022;63:573–97. https://doi.org/10.1111/epi.17135.

[12] Mbuba CK, Abubakar A, Odermatt P, Newton CR, Carter JA. Development and validation of the Kilifi Stigma Scale for Epilepsy in Kenya. Epilepsy & Behavior 2012;24:81–5. https://doi.org/10.1016/j.yebeh.2012.02.019.

[13] Taylor J, Baker GA, Jacoby A. Levels of epilepsy stigma in an incident population and associated factors. Epilepsy Behav 2011;21:255–60. https://doi.org/10.1016/j.yebeh.2011.04.002.

[14] Fernandes PT, Salgado PCB, Noronha ALA, Sander JW, Li LM. Stigma scale of epilepsy: validation process. Arq Neuro-Psiquiatr 2007;65:35–42. https://doi.org/10.1590/S0004-282X2007001000006.

[15] World Bank Group country classifications by income level for FY24 (July 1, 2023- June 30, 2024) 2023. https://blogs.worldbank.org/opendata/new-world-bank-group-country-classifications-income-level-fy24 (accessed September 8, 2023).

[16] Circle. Population - National Statistics Office of Georgia n.d. https://www.geostat.ge/en/modules/categories/41/population (accessed September 8, 2023).

[17] Gzirishvili N, Kasradze S, Lomidze G, Okujava N, Toidze O, de Boer HM, et al. Knowledge, attitudes, and stigma towards epilepsy in different walks of life: A study in Georgia. Epilepsy & Behavior 2013;27:315–8. https://doi.org/10.1016/j.yebeh.2013.02.011.

[18] Berto P. Quality of Life in Patients with Epilepsy and Impact of Treatments: PharmacoEconomics 2002;20:1039–59. https://doi.org/10.2165/00019053-200220150-00002.

[19] Poochikian-Sarkissian S, Sidani S, Wennberg RA, Devins GM. Psychological impact of illness intrusiveness in epilepsy - comparison of treatments. Psychol Health Med 2008;13:129–45. https://doi.org/10.1080/13548500701294515.

[20] DiIorio C, Osborne Shafer P, Letz R, Henry T, Schomer DL, Yeager K, et al. The association of stigma with self-management and perceptions of health care among adults with epilepsy. Epilepsy Behav 2003;4:259–67. https://doi.org/10.1016/s1525-5050(03)00103-3.

[21] Whatley AD, DiIorio CK, Yeager K. Examining the relationships of depressive symptoms, stigma, social support and regimen-specific support on quality of life in adult patients with epilepsy. Health Educ Res 2010;25:575–84. https://doi.org/10.1093/her/cyq001.

[22] Wu Y, Huang K, Wen S, Xiao B, Feng L. Validation of the Chinese Version of the Stigma Scale of Epilepsy. Front Neurol 2022;13:796296. https://doi.org/10.3389/fneur.2022.796296.