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Evaluation of self-stigma in patients with epilepsy: Validation of the self-stigma scale to Montenegrin language

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Abstract

This study aimed to adapt and validate the Montenegrin version of the Epilepsy Self-Stigma Scale (ESSS-MNE) to assess internalized stigma among people with epilepsy (PWE) in Montenegro. Epilepsy-related stigma remains a pervasive issue globally, adversely affecting self-esteem, social integration, and treatment adherence. Cultural and linguistic specificity is critical in accurately measuring self-stigma, particularly in understudied populations like Montenegro.

The ESSS was translated and culturally adapted using a forward-backward method, followed by psychometric validation in a sample of 230 adult PWE recruited from a tertiary care center. Both exploratory and confirmatory factor analyses supported a unidimensional structure with acceptable model fit (CFI = 0.911, RMSEA = 0.097). Internal consistency was satisfactory (Cronbach's α = 0.77). Higher self-stigma scores were significantly associated with unemployment, single marital status, lower education, and polytherapy.

The ESSS-MNE is a valid and reliable tool for measuring self-stigma in Montenegrin PWE. Its use can support clinical assessment, inform targeted anti-stigma interventions, and enable cross-cultural comparisons. Future studies should explore its applicability in broader and more diverse populations.

1. Introduction

Epilepsy is a chronic neurological disorder characterised by recurrent seizures that affects over 50 million individuals globally, transcending racial, national, and geographical boundaries.

[1, 2] Despite its prevalence, epilepsy remains one of the most misunderstood disorders, often leading to significant stigma and discrimination against those affected. Almost 30 years ago, Kale outlined the history of epilepsy as "4,000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma". [3] This pervasive lack of understanding among general population and ignorance has fostered negative attitudes towards people with epilepsy (PWE), which in turn exacerbate the stigma they experience.

The concept of stigma concerning epilepsy is a universal phenomenon, prevalent across diverse cultures regardless of historical contexts, economic conditions, or social norms. [2] Stigma manifests in various forms, negatively impacting the lives of PWE by diminishing their self-esteem and undermining their sense of self-worth. This is particularly evident in the context of Montenegro, where the prevalence of epilepsy is estimated at 1.3% [4], underscoring its role as a substantial public health concern.

The unpredictable nature of epileptic seizures and occasionally their dramatic manifestations often induces fear, anxiety and shame not only in PWE but also among their caregivers. This has historically engendered negative societal attitudes, framing epilepsy within a context of misconceptions that associate it with madness or demonic possession. [5] Such linguistic associations further perpetuate discriminatory views, with terms used to describe epilepsy often carrying derogatory connotations.

Despite advancements in our understanding of epilepsy as a disorder rooted in abnormal neuronal activity, deeply ingrained stigma persists across all cultures. Individuals with epilepsy frequently face multifaceted prejudices, including perceptions of mental incapacity, barriers to education, limitations in sports participation, challenges in securing employment, and societal discouragement from marriage and parenting. This dual burden of living with a neurological disorder, facing social stigma leads to everyday unspoken battles that severely impacts their quality of life, causing them to keep their disorder a secret. PWE and their families may be further challenged with a lack of social support and discrimination due to misperceptions not only by the public but also by their own family or even themselves. Stigma thus impact the most those who are already marginalised and disempowered. [6]

To combat the stigma surrounding epilepsy, it is essential to share, compare, and contrast research findings across developed and resource-poor countries. Such collaboration could facilitate the development of effective strategies aimed at alleviating stigmatization, ultimately assisting patients in reclaiming their self-esteem and reintegrating as valued members of society. Addressing the stigma of epilepsy is a universal challenge that demands urgent attention, as its resolution has the potential to uplift the lives of millions of individuals affected by this chronic condition.

Self-stigma, the internalization of societal prejudices, profoundly impacts PWE, manifesting as diminished self-esteem, social withdrawal, and treatment nonadherence. Rooted in misconceptions—such as associating seizures with instability or danger—self-stigma exacerbates the psychosocial burden of epilepsy. [7, 8] Globally, tools like the Epilepsy Self-Stigma Scale (ESSS) have been developed to measure this phenomenon, yet their cross-cultural applicability remains limited. [8–10] This underscores the need for a Montenegrin ESSS, tailored to capture the unique socio-cultural dynamics influencing stigma in Montenegro.

Cultural context significantly shapes stigma experiences. In Montenegro, historical, religious, and familial norms may propagate distinct stereotypes about epilepsy, diverging from Western contexts where existing scales originated. Direct translation of existing tools risks overlooking these nuances, as idioms like "sramota" (shame) or "društvena isključenost" (social exclusion) may carry culturally specific connotations. A localized ESSS ensures alignment with Montenegrin expressions of stigma, enhancing measurement validity.

Montenegro lacks validated instruments to quantify self-stigma in PWE. Clinicians relying on translated tools may misinterpret responses, compromising care quality. A culturally adapted ESSS would address this gap through rigorous psychometric validation, including translation-back-translation and pilot testing with Montenegrin PWE. Data from a localized ESSS could inform public health campaigns targeting pervasive myths, such as educational programs in schools to reduce peer stigma. Additionally, self-stigma correlates with comorbid mental health disorders, such as depression and anxiety, prevalent in 30–50% of PWE. A Montenegrin ESSS would enable clinicians to identify at-risk individuals, facilitating early psychosocial interventions.

Developing a Montenegrin ESSS enriches global epilepsy research by diversifying datasets beyond high-income countries. Comparative studies using localized scales could reveal cross-regional stigma drivers, informing transnational anti-stigma efforts. Furthermore, inclusion of Montenegrin data ensures representation in global health policies, advancing equity in epilepsy care.

Therefore, given the absence of a validated tool to assess epilepsy-related stigma in Montenegro, the present study aims to adapt and validate a Montenegrin version of the [ESSS-MNE], thereby providing a culturally relevant instrument to facilitate both national research and international comparisons.

2. Methods

2.1 Translation and Cultural Adaptation Process

The Montenegrin version of the Epilepsy Self-Stigma Scale (ESSS-MNE) was developed following standard procedures for cross-cultural adaptation of psychometric instruments. The original ESSS was first translated from English into Montenegrin by two independent bilingual translators. A reconciliation process was conducted to produce a single forward translation. This version was then back-translated into English by two other independent translators who were blinded to the original version.

Discrepancies between the original and back-translated versions were reviewed by an expert panel consisting of psychiatrists, neurologists, and linguistic specialists. Adjustments were made to resolve semantic inconsistencies while preserving conceptual equivalence. Feedback from professional linguists and a cognitive debriefing analysis with a small sample of individuals with epilepsy ensured clarity, cultural appropriateness, and relevance of the translated items.

The final version of the ESSS-MNE was agreed upon after incorporating feedback and ensuring consistency across all translations. This version was then used in the validation phase of the study.

2.2 Participants and Procedures

This cross-sectional study was conducted between April and July 2025 at the Clinical Center of Montenegro, a tertiary care hospital that serves as the country's central referral institution for neurological disorders. Participants were adult patients with a confirmed diagnosis of epilepsy, who were consecutively recruited from the outpatient neurology clinic during routine follow-up visits. The diagnosis of epilepsy was established according to the criteria of the International League Against Epilepsy (ILAE), and only patients with a disease duration of at least 12 months were considered for inclusion.

To be eligible for the study, participants had to be 18 years of age or older, possess sufficient proficiency in the Montenegrin language to comprehend the questionnaire, and be capable of providing written informed consent. Patients with comorbid severe psychiatric conditions, such as psychotic disorders or profound intellectual disability, were excluded from the study, as were those with significant cognitive or physical impairments that would interfere with the ability to complete the self-administered

questionnaire. Individuals who declined to participate or withdrew consent were also excluded from analysis.

Following a detailed explanation of the study's purpose and procedures, patients who agreed to participate were asked to complete a set of instruments, including the Montenegrin version of the Epilepsy Self-Stigma Scale (ESSS-MNE), as well as a sociodemographic and clinical information form. This supplementary questionnaire collected data on age, sex, educational attainment, employment status, type of seizures, duration of epilepsy, and current treatment regimen. Completion of the survey materials typically required between 10 and 15 minutes.

All participants provided written informed consent prior to enrollment. The study was reviewed and approved by the Ethics Committee of the Clinical Center of Montenegro (Etički komitet kloničkog centra Crne Gore - approval number: 03/01-12644) and was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki.

2.3 Measures

The primary instrument used to assess self-stigma in this study was the Montenegrin version of the Epilepsy Self-Stigma Scale (ESSS-MNE), which was translated and culturally adapted from the original Japanese version[7] using a standardized forward–backward translation procedure. The ESSS was originally developed to measure the subjective experience of stigma among people with epilepsy (PWE), capturing internalized beliefs and attitudes toward their condition.

The ESSS-MNE consists of 8 self-report items rated on a 4-point Likert scale ranging from 1 ("strongly disagree") to 4 ("strongly agree"). Higher scores indicate greater levels of self-stigma. The total score is calculated by summing the item scores, resulting in a possible range from 8 to 32 points. The scale is designed to be brief and easy to administer, making it suitable for use in clinical and research settings.

In addition to the ESSS-MNE, participants completed a brief demographic and clinical questionnaire that collected information on age, sex, educational level, employment status, seizure types (generalized, focal, or unclear), duration of epilepsy, and current treatment with anti-seizure medications (ASMs). These variables were included to explore potential correlates of self-stigma and to characterize the study population.

The original ESSS was developed with a unidimensional structure, and this assumption was examined in the current study using both exploratory and confirmatory factor analyses.

Although the original ESSS also proposed three subdimensions, these have not been consistently replicated in previous studies; therefore, the total score is often used in cross-national research. [8–10]

2.4 Statistical Analysis

First, descriptive statistics were calculated for demographic variables, including age, gender, educational attainment, employment status, and marital status.

Next, to examine the factor structure of the ESSS, an exploratory factor analysis (EFA) was conducted using maximum likelihood estimation with promax rotation. The number of factors to retain was determined based on eigenvalues greater than 1.0, the scree plot, and the interpretability of factor loadings.

Subsequently, confirmatory factor analysis (CFA) was performed to test the hypothesized unidimensional structure of the scale. Model fit was evaluated using multiple indices: the comparative fit index (CFI), the root mean square error of approximation (RMSEA). Acceptable model fit was defined as CFI ≥ .90, RMSEA ≤ .08. [11]

Finally, internal consistency reliability was assessed using Cronbach's alpha coefficient, and associations between ESSS total scores and demographic variables were examined. Pearson's correlation coefficient was used for age and duration of epilepsy, and independent-samples t-tests or one-way ANOVAs were conducted for categorical variables, as appropriate. For ANOVAs, Bonferroni-adjusted pairwise comparisons were applied in post hoc analyses to control for Type I error.

The effect size was calculated and evaluated according to the following standards[12]: For t-tests, Cohen's d was used, with standards set at small (0.20 to 0.49), medium (0.50 to 0.79), and large (≥ 0.80). For ANOVA, η^2 was used to assess the strength of the association between the variable in question and the dependent variable, with standards set at small (0.01 to 0.059), medium (0.06 to 0.139), and large (≥ 0.14).

All analyses were performed using IBM SPSS Statistics version 30, except for the CFA, which was conducted using IBM SPSS Amos version 30 (IBM Corp., Armonk, NY, USA).

3. Results

3.1 Participant Characteristics

A total of 230 individuals with epilepsy participated in the study (Table 1). The mean age of the participants was 33.0 years (SD = 11.6), with a range from 18 to 63 years. Of the total sample, 127 (55.2%) were female. Regarding educational background, 183 (79.6%) had completed secondary school, while 47 (20.4%) had a university-level education. Nearly half of the participants, 113 (49.1%) were unemployed at the time of the study. In terms of marital status, 157 (68.3%) reported being single, 30 (13.0%) were in a relationship, and 43 (18.7%) were married.

With respect to seizure types, 105 participants (45.7%) had generalized epilepsy, 96 (41.7%) had focal epilepsy, and 29 (12.6%) were classified as unclear. The mean duration of epilepsy was 7.86 years (SD = 6.27). Regarding treatment, 150 participants (65.2%) were receiving monotherapy, while 80 (34.8%) were on polytherapy with ASMs.

The participants completed the Montenegrin version of the Epilepsy Self-Stigma Scale (ESSS-MNE), which consists of 8 items scored on a 4-point Likert scale. The total ESSS-MNE scores ranged from 9 to 30, with a mean score of 19.2 (SD = 4.6). The distribution was approximately normal, with 25% of participants scoring 16 points or below, and 25% scoring above 22.

Table 1
Descriptive statistics for demographic variables and ESSS-MNE scores

	Summary
N	230
Age (years)	33.0 (11.6)
Sex	
female	127 (55.2)
male	103 (44.8)
Educational attainment	
secondary school	183 (79.6)
university	47 (20.4)
Employment status	
unemployed	113 (49.1)
employed	117 (50.9)
Marrital status	
single	157 (68.3)
in a relationship	30 (13.0)
married	43 (18.7)
Types of epilepsy	
generalized	105 (45.7)
focal	96 (41.7)
unclear	29 (12.6)
Duration of epilepsy (years)	7.86 (6.27)
Types of epilepsy	
Monotherapy	150 (65.2)
Polytherapy	80 (34.8)
ESSS-MNE	19.2 (4.6)
Note. Mean (SD); N (%)	
ASMs; antiseizure medications	

3.2 Examination of Factorial Validity

Exploratory factor analysis using maximum likelihood extraction with Promax rotation identified two factors with eigenvalues greater than 1.0, although the second factor comprised only three items and the overall pattern was not consistent with the original three-factor model. Item 6 (“Few people have the correct information about the disease of epilepsy”) showed factor loadings below .20 on both factors in the two-factor solution, indicating that it did not clearly align with either factor; however, it was retained to preserve the original eight-item composition of the ESSS and to ensure comparability with previous international studies.

Subsequently, confirmatory factor analysis (CFA) was conducted to examine the hypothesized unidimensional structure of the scale. The results indicated: CFI = 0.911, RMSEA = 0.097 (90% CI [0.071, 0.125]). While the CFI met the predefined cutoff (≥ .90), the RMSEA was slightly above the recommended threshold, indicating a reasonable, albeit marginal, fit. All items loaded significantly on the latent factor, except for item 6, which showed only a marginally significant loading. The results for the one-factor solution are provided separately in Table 2.

Table 2
Standardized factor loadings for the ESSS-MNE (one-factor CFA)

Item	Standardized Estimate	SE	p
esss-mne_7	0.81	0.18	< .001
esss-mne_4	0.68	0.16	< .001
esss-mne_3	0.65	0.18	< .001
esss-mne_2	0.64	0.15	< .001
esss-mne_5	0.59	0.15	< .001
esss-mne_1	0.58	0.22	< .001
esss-mne_8	0.46	0.13	< .001
esss-mne_6	0.14	0.12	0.06
Note. SE = standard error.			

Given the theoretical unidimensionality of the ESSS and the importance of cross-national comparability, all eight items were retained, and a single total score was used in subsequent analyses. Detailed results of the two-factor solution from the exploratory analysis are presented in Appendix A.

3.3 Reliability

Internal consistency of the eight-item ESSS-MNE was acceptable (Cronbach's α = .77). Removing item 6 ("Few people have the correct information about the disease of epilepsy") increased the coefficient to .82; however, the value for the full eight-item scale was still within the acceptable range. In order to maintain consistency with the original scale and ensure comparability with previous international studies, all eight items were retained in the total score.

3.4 Associations Between ESSS Scores and Demographic Variables

Pearson's correlation analysis showed no significant association between ESSS-MNE total scores and age or epilepsy duration ($r = 0.10$, $p = 0.14$; $r = 0.07$, $p = 0.27$). As shown in Table 3, ESSS-MNE scores did not differ significantly between females and males ($t(228) = -0.47$, $p = 0.64$, $d = 0.06$).

As also presented in Table 3, no significant differences in ESSS-MNE scores were observed for sex ($t = -0.47$, $p = 0.64$, $d = 0.06$) or seizure type ($F = 2.07$, $p = 0.13$, $\eta^2 = 0.02$). In contrast, participants with secondary school education scored significantly higher than those with a university education ($t = 2.63$, $p = 0.01$, $d = 0.35$), and unemployed participants scored significantly higher than employed participants ($t = -5.73$, $p < 0.001$, $d = 0.76$). Regarding marital status, a one-way ANOVA revealed a significant difference among the three groups ($F = 13.50$, $p < 0.001$, $\eta^2 = 0.11$). Post hoc Bonferroni comparisons indicated that single participants scored significantly higher than those in a relationship ($p < 0.001$) and those who were married ($p = 0.01$), whereas the latter two groups did not differ significantly ($p = 0.16$). Moreover, participants receiving polytherapy scored significantly higher than those receiving monotherapy ($t = -8.05$, $p < 0.001$, $d = 4.10$).

Table 3
Group comparison results for ESSS-MNE scores by demographic variables

Variable	Group 1 (M ± SD)	Group 2 (M ± SD)	Group 3 (M ± SD)	t/F	p	Effect size	Post hoc comparisons
Sex	female (n = 127)	male (n = 103)					
	19.09 ± 4.40	19.38 ± 4.93		-0.47	0.64	0.06	
Education attainment	secondary (n = 183)	university (n = 47)					
	19.55 ± 4.86	17.94 ± 3.40		2.63	0.01	0.35	
Employment status	unemployed (n = 113)	employed (n = 117)					
	20.90 ± 5.50	17.59 ± 2.80		5.73	< 0.001	0.76	
Marital status	single (n = 157)	in a relationship (n = 30)	married (n = 43)				
	20.17 ± 4.95	15.97 ± 2.58	18.00 ± 3.02	13.5	< 0.001	0.11	1 > 2; 1 > 3
Types of epilepsy	generalized (n = 105)	focal (n = 96)	unclear (n = 29)				
	18.54 ± 4.75	19.76 ± 4.45	19. 86 ± 4.70	2.07	0.13	0.02	
Types of ASMs	monotherapy (n = 150)	polytherapy (n = 80)		-8.05	< 0.001	4.10	
	17.63 ± 3.72	22.2 ± 4.74					

Note. Effect sizes are reported as Cohen's d for all variables except marital status, for which η^2 is reported. ASMs; antiseizure medications

4. Discussion

The present study examined the psychometric properties of the Montenegrin version of the Epilepsy Self-Stigma Scale (ESSS-MNE) among adults with epilepsy. Exploratory factor analysis suggested a two-

factor solution, whereas confirmatory factor analysis supported a unidimensional model with an acceptable level of model fit. These results indicate that, although some item clusters may represent distinct aspects of self-stigma, the ESSS-MNE can be appropriately conceptualized as measuring a single overarching construct in this population.

Compared to the original Japanese version [7] and other translated versions [8-10], the factor structure in this study showed partial similarity but also notable differences. In the original validation studies, a unidimensional structure was consistently supported. The emergence of a two-factor pattern in the EFA may reflect cultural nuances in the experience and expression of stigma among people with epilepsy in Montenegro, as well as sample characteristics such as clinical setting and sociodemographic composition. Nonetheless, the CFA results, which confirmed a single-factor structure, are consistent with the theoretical framework underlying the scale.

One noteworthy finding from the analysis was the suboptimal psychometric performance of item 6, which demonstrated particularly low factor loadings and a weak item–total correlation. This item assesses respondents' perceptions of public knowledge regarding epilepsy, a construct which that may not directly measure an individual's internalized stigma but rather reflects their views on societal awareness. Within the Montenegrin sociocultural context, public discourse surrounding epilepsy remains limited, and persistent misconceptions prevail. A prior study by Vodopic et al. [13] highlighted predominantly negative societal attitudes toward epilepsy, influenced by regional disparities (e.g. urban vs. rural residence), traditional belief systems, small community dynamics. Consequently, responses to Item 6 could reflect general societal commentary rather than self-referential attitudes.

Further contextualizing findings from a paper by Vodopic et.al [13], this study identified entrenched sociocultural biases against epilepsy in Montenegro, compounded by systemic inadequacies in healthcare infrastructure. The national healthcare system lacks dedicated epilepsy nursing roles, specialized patient/caregiver resources, and regionally equitable access to care—disparities disproportionately affecting northern and rural populations. Historically, cultural norms emphasizing concealment of the condition have been deeply rooted, prompting individuals to seek solace in religious institutions rather than medical care. While contemporary monotheistic religious frameworks increasingly recognize epilepsy as a medical disorder [14], but with varying influence. Nevertheless, positive religious coping strategies and even targeted public health campaigns hold significant potential to mitigate stigma, enhance mental health outcomes, and improve quality of life for affected individuals. [14]

The sociocultural framework of Montenegro emphasizes strong familial and communal values, a pattern consistent with other monotheistic societies. [10] While these collective norms can foster social cohesion, they also present a double-edged sword, as culturally entrenched beliefs may perpetuate misinformation and stigmatising attitudes, thereby shaping public perceptions of epilepsy. This distinction may explain its weaker association with the latent construct measured by the ESSS-MNE. Although removing item 6 slightly improved internal consistency, the item was retained to

preserve the original content and to enable cross-cultural comparisons with prior studies using the full 8-item scale.

Community knowledge and awareness significantly influences societal stigma toward individuals with epilepsy [15,16] yet its role in mitigating self-stigmatization remains complex. While health literacy is foundational, empirical evidence suggests that self-stigma reduction requires not only disease-specific knowledge but also experiential reinforcement through affirming psychosocial interactions. [8] Positive lived experiences—integrated with health literacy—may foster resilience, self-efficacy, and identity reclamation, thereby disrupting internalized stigmatization.

At a structural level, stigma propagation often correlates with systemic health education disparities, where prejudicial attitudes are amplified in regions with limited access to validated information or culturally competent care. This underscores the necessity of transcending knowledge dissemination as a standalone intervention. Comparative cross-national investigations are urgently needed to delineate how cultural narratives, socioecological determinants, and intersectional identities modulate stigma trajectories. Multicultural frameworks are critical to advancing universal conceptual models of self-stigma while preserving context-specific mediating pathways. Such research will inform scalable, evidence-based anti-stigma interventions that harmonize public education

Regarding associations with demographic variables, employment status and marital status were significantly related to ESSS-MNE scores. Unemployed participants reported higher levels of self-stigma than employed participants, and single individuals reported higher scores than those in a relationship or married.

The prevalence of unemployment and underemployment among PWE surpasses that of the general population [17-19] and these individuals often encounter greater challenges in maintaining their employment Research indicates that only 39% of people with epilepsy (PWE) are employed full-time, compared to 55% of individuals without epilepsy, with one third of PWE facing unemployment, in contrast to 13% in the control group. [20] Studies further demonstrate that approximately 50% of PWE who are employed choose not to disclose their condition to potential employers. [21] This reluctance frequently stems from employers' misconceptions regarding accidents and absenteeism, leading to an unjust burden of employment restrictions based on stereotypes. [21,22] Notably, the incidence of workplace accidents among PWE is comparable to that of their non-epileptic counterparts. [23]

The stigma associated with epilepsy may discourage affected individuals from pursuing further education, thus limiting their career opportunities and perpetuating a cycle of disadvantage. In the context of government-supported initiatives for individuals with disabilities, the fear of stigma and uncertainty regarding work longevity often deter applications. Psychosocial factors significantly influence the employment opportunities and overall quality of life for PWE, yet the diversity and complexity of these factors complicate the ability to identify precise relationships between psychosocial variables and employment status.Research frequently highlights low self-efficacy among PWE, coupled

with a tendency to employ passive coping strategies to navigate their challenges. These dynamics can create a detrimental cycle related to employment. [24]

Social norms that equate personal value with career and family roles often cultivate internalized shame among individuals whose lives diverge from these expectations. When societal frameworks disproportionately emphasize employment and traditional relationships as measures of success, those navigating joblessness or unconventional family structures frequently absorb damaging cultural narratives about their worth.[25] In professional contexts, chronic unemployment often attracts perceptions of unreliability or underachievement, despite systemic factors like economic downturns or workplace discrimination. This persistent labeling gradually undermines people's sense of purpose and agency, creating cycles of self-doubt where individuals question their abilities rather than critiquing flawed societal metrics of productivity. [26]

Research indicates a positive correlation between single status and higher levels of stigma among PWE. This association implies that those who are unmarried may endure increased internalized shame or anxiety regarding potential discrimination associated with their condition. Contributing factors to this heightened stigma may include reduced social support, unfavorable economic conditions, and specific characteristics of epilepsy, such as frequent seizure activity or a history of significant injuries. [27-31]

No significant differences were found between men and women, and age was not significantly correlated with ESSS-MNE scores. These findings align with previous research [7,9,10] suggesting that social integration and supportive relationships may act as protective factors against internalized stigma.

Participants receiving polytherapy scored significantly higher than those receiving monotherapy. Studies reveal that individuals managed with multi-drug regimens for epilepsy demonstrate elevated markers of internalized stigma compared to those on single-drug approaches. [32] While pharmacological intervention remains critical for seizure management, neither treatment complexity nor medication quantity directly correlate with improvements in social integration—a domain profoundly impacted in PWE.[30] While single-drug protocols are ideal for minimizing side effects, even optimized seizure control often fails to address psychosocial challenges. This underscores the necessity for parallel interventions targeting community engagement and stigma reduction alongside traditional medical care. Multi-drug regimens frequently reflect refractory cases, which are independently associated with diminished daily functioning, heightened psychiatric burdens, and amplified perceptions of social exclusion. [32,34] Critically, the interplay between persistent seizures, polypharmacy consequences, and societal attitudes creates a self-reinforcing cycle—where treatment burdens exacerbate social limitations, which in turn intensify health-related anxieties. These findings advocate for holistic care frameworks that decouple clinical success from seizure suppression metrics, prioritizing patient-reported psychosocial outcomes with equal rigor. [32]

5. Limitations

Several limitations of this study should be acknowledged. First, the sample was drawn from a single tertiary care center in Montenegro, which may limit the generalizability of the findings to the broader population of people with epilepsy, particularly those in rural or underserved regions who may have different experiences of stigma or barriers to care.

Second, test–retest reliability was not assessed, and therefore the temporal stability of the ESSS-MNE scores remains unexamined.

Third, the validity assessment was limited to factorial validity. Unlike the original version and other translated versions of the scale, convergent validity was not evaluated because no related measures were administered. Due to lack of Montenegrin version of relevant scales, these measures were not included.

Fourth, the cross-sectional design of the study precludes any inference regarding the directionality or causality of the observed associations between self-stigma and clinical or sociodemographic factors.

Lastly, the study relied solely on self-report measures, which may be subject to response biases, including social desirability and recall bias.

Taken together, these limitations highlight the need for future research to recruit more diverse samples, employ longitudinal designs, incorporate multiple assessment methods—including clinician assessments and qualitative interviews—and evaluate a broader range of psychometric properties, including test–retest reliability and convergent validity, to more comprehensively establish the utility of the ESSS-MNE.

6. Conclusion

In conclusion, the evaluation of self-stigma among people with epilepsy in Montenegro, utilising the adapted Epilepsy Self-Stigma Scale (ESSS-MNE), has illuminated critical insights into the psychological burdens faced by this population. The findings of this study reveal a concerning prevalence of self-stigma, which appears to be influenced by various demographic factors such as employment status and marital status, with unemployed and single individuals reporting higher levels of internalized stigma. Despite the recognition of epilepsy as a neurological disorder, societal misconceptions and persistent stigma continue to undermine the self-esteem and quality of life of those affected.

The psychometric validation of the ESSS-MNE demonstrates its applicability in capturing the nuanced experiences of stigma within the Montenegrin context, although the emergence of different factor structures suggests the need for ongoing exploration of cultural influences on stigma perceptions. The study underscores the importance of addressing public misconceptions through education and supportive frameworks, as well as enhancing community awareness to mitigate stigma and foster resilience among individuals with epilepsy. Future research should continue to focus on the sociocultural determinants of stigma, exploring effective interventions that can transform societal attitudes, restore

self-efficacy, and improve the overall outcomes for individuals living with epilepsy. As stigma remains a significant barrier to social integration and employment opportunities, comprehensive strategies are essential to empower people with epilepsy and facilitate their reintegration as valued participants in society.

Declarations

Ethics approval and consent to participate

This study was conducted following the approval of the study protocol by the Ethics Committee of the Clinical Center of Montenegro (Etički komitet kloničkog centra Crne Gore - approval number: 03/01-12644) and was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. Participation was voluntary, and information was collected anonymously after obtaining written consent from each respondent. Participants were assured that their data would be kept confidential throughout the data collection period. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Declaration of competing interest

Authors have nothing to declare

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Availability of data and materials

Our research data has not been deposited into a publicly available repository. The authors have archived the raw data supporting the conclusions of this article. Due to confidentiality obligations, the data will not be made available to the general. If requested by other researchers, the authors will provide the data. Please contact the corresponding author if necessary.

SG – Writing – original draft, Visualization, Validation, Project administration, Methodology, Investigation, Conceptualization. **IK:** Writing – review & editing, Supervision, Methodology, Conceptualization. **TI:** Writing – review & editing, Validation, Software, Methodology, Formal analysis. **DM:** Writing – review & editing.

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