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REVIEW ARTICLE

Epilepsy-specific quality-of-life questionnaires and social stigma scales in adults with epilepsy: a methodological review

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ABSTRACT

Introduction. Adult epilepsy generates a burden that extends beyond seizure counts and includes adverse treatment effects, role restriction, emotional distress, and the social devaluation attached to the diagnosis. The methodological problem is not the absence of patient-reported measures, but the heterogeneity with which disease-specific quality-of-life and stigma instruments are selected, interpreted, and combined in adult studies.

Materials and methods. A structured narrative methodological review was conducted using PubMed/MEDLINE, Scopus, Web of Science, Embase, Cochrane Library, and the institutional repository of the *Nicolae Testemițanu* State University of Medicine and Pharmacy. The synthesis focused on the Quality of Life in Epilepsy Inventory family, especially the 89-, 31-, 31-P, and 10-item forms, the adolescent 48-item comparator, and adult epilepsy stigma measures such as the Epilepsy Stigma Scale (ESS) variants, the Stigma Scale of Epilepsy (SSE), and the Epilepsy Self-Stigma Scale (ESSS). Special attention was given to publications from the Republic of Moldova and Romania because regional evidence is sparse but clinically relevant.

Results. QOLIE-31 emerged as the most defensible adult comparative instrument because it balances breadth, feasibility, and international comparability. QOLIE-31-P was particularly useful for patient-centred and real-world designs, while QOLIE-10 served primarily as a screening instrument and QOLIE-89 retained value for comprehensive psychometric work. The 48-item version was methodologically informative but remained adolescent-oriented rather than a primary adult endpoint. Across the stigma literature, ESS, SSE, and ESSS were clearly not interchangeable because they capture overlapping but distinct constructs, including perceived stigma, felt stigma, and internalized self-stigma.

Conclusions. The working hypothesis was supported across international, regional, and Moldovan sources: the greater the clinical and psychosocial severity of epilepsy, the lower the epilepsy-specific quality of life. Seizure frequency, uncontrolled or drug-resistant epilepsy, polytherapy, adverse medication effects, depression, anxiety, and stigma were the most recurrent determinants of lower scores. For adult studies intended for Moldovan settings and the MJHS submission, QOLIE-31 or QOLIE-31-P, combined with one clearly defined stigma scale and a standardized set of severity variables, offers the strongest methodological balance.

Keywords: epilepsy, quality of life, social stigma, patient-reported outcome measures, questionnaires, narrative review.

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Key messages

What is not yet known on this issue addressed in the submitted manuscript

Adult epilepsy research uses multiple disease-specific quality-of-life and stigma instruments, but the Eastern European and

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Moldovan academic community has rarely organized these tools according to construct differences, respondent burden, and study design.

The research hypothesis

Reduced seizure control, higher treatment burden, and stronger perceived or internalized stigma are associated with poorer epilepsy-specific quality-of-life scores across adult studies, regardless of the exact questionnaire version.

The novelty added by the manuscript to the already published scientific literature

This review integrates international, Romanian, and Moldovan literature, converting that evidence into a practical adult questionnaire strategy for future Moldovan epilepsy studies.

Introduction

Epilepsy is among the chronic neurological conditions in which biomedical control and the lived burden do not always move in parallel. Two adults with the same nominal seizure diagnosis can report very different levels of daily restriction because the quality of life in epilepsy is shaped not only by seizure occurrence, but also by medication burden, unpredictability, fear of recurrence, limitations on driving and employment, interpersonal strain, and the social meaning attached to the disorder. For that reason, epilepsy research that reports only seizure outcomes risks underestimating clinically relevant morbidity. Systematic review evidence has repeatedly shown that the health-related quality of life in adults with epilepsy is most strongly eroded by high seizure frequency, depression, anxiety, adverse effects of anti-seizure medication, and broader psychosocial strain [1, 2].

Stigma occupies a special place in this burden architecture because it works simultaneously at social, interpersonal, and intrapsychic levels. Quantitative and qualitative reviews show that adults with epilepsy encounter enacted discrimination, anticipated rejection, concealment behavior, diminished self-worth, and reduced help-seeking; these effects are shaped by illness severity but are not reducible to it. In other words, stigma is not a decorative psychosocial theme added to seizure medicine after the real work is done. It is a mechanism that alters adherence, participation, family functioning, and even the perceived legitimacy of one's own symptoms. Moldovan authors have framed this issue in similar terms, emphasizing that stigmatization and self-stigmatization alter self-perception, reduce self-esteem, affect treatment adherence, and ultimately worsen quality of life [3-5].

The public-health salience of epilepsy stigma has long been recognised internationally. The ILAE/IBE/WHO global campaign "Out of the Shadows" was built on the premise that seizure control alone is not enough if communities continue to mark epilepsy as a condition associated with fear, incompetence, unpredictability, or social inferiority. That insight remains methodologically important because it explains why adult epilepsy research cannot choose instruments as if they all measured a single undifferentiated outcome. A quality-of-life inventory, a perceived-stigma scale, and a self-stigma measure each illuminates a different layer of the patient experience. The more rigorously these constructs are separated, the more interpretable the findings become [6-8].

The best-known disease-specific quality-of-life tools in epilepsy derive from the Quality of Life in Epilepsy Inventory family. QOLIE-89 was developed as the comprehensive parent measure, QOLIE-31 as the more feasible short form for adult comparative work, and QOLIE-10 as a very brief screening instrument. A further 48-item instrument, QOLIE-AD-48, extended the same logic to adolescents rather than adults. Official RAND documentation still presents QOLIE-89 and QOLIE-31 as publicly available survey instruments with scoring manuals, which is valuable for transparency, reproducibility, and local implementation planning. Yet public availability does not solve the deeper methodological problem: each version has a different trade-off between construct richness, respondent burden, and suitability for longitudinal, psychometric, or routine-care use [9-13].

A parallel problem exists in the stigma literature. Across the international adult literature, the abbreviations ESS, SSE, revised ESS, and ESSS are easy to conflate even when they refer to different instruments or to translated variants targeting different stigma domains. Some scales emphasize perceived or felt stigma in everyday social encounters; others move closer to internalized self-stigma or to culturally embedded social discrediting. When investigators refer loosely to "stigma" without naming the construct and instrument precisely, the literature becomes deceptively coherent. In reality, it contains multiple partially overlapping constructs that cannot be pooled naively. This ambiguity matters even more in low-volume national literatures, where a single study can influence local practice disproportionately [14-18].

In the Republic of Moldova, the need for a construct-sensitive approach is especially evident. The adult national clinical protocol formalizes standardized diagnostic and therapeutic pathways and explicitly places quality of care and patient outcomes at the centre of adult epilepsy management. Local scholarly work has also highlighted stigma, adaptation, resocialization, and psychological rehabilitation as clinically meaningful dimensions rather than peripheral

social commentary. Recent Romanian studies add a relevant Eastern European comparator by showing that QOLIE-31-P is operationally feasible in real-life neurology practice and that seizure frequency remains a powerful inverse predictor of epilepsy-specific quality of life over time. These regional contributions justify a dedicated methodological synthesis that moves from general knowledge to a practical questionnaire strategy for future Moldovan adult research [19-24].

The aim of the present review was therefore to examine how epilepsy-specific quality-of-life questionnaires and adult stigma scales are used in adult epilepsy research, to interpret their findings in relation to epilepsy severity and study design, and to integrate international evidence with regional and Moldovan publications. The working hypothesis was that poorer seizure control, greater treatment burden, and stronger perceived or internalized stigma are associated with worse epilepsy-specific quality-of-life scores regardless of the exact questionnaire version. A secondary objective was pragmatic: to identify which instrument combinations appear most suitable for future Moldovan adult studies prepared for the MJHS [20, 21, 25].

Materials and methods

This manuscript was designed as a narrative methodological review rather than a systematic review or meta-analysis. The choice was deliberate. The central question was not simply whether epilepsy severity correlates with quality-of-life or stigma scores, since that pattern is already well documented, but how different questionnaires operationalize adult burden, what methodological tasks they perform best, and how a Moldovan research team should choose among them. Narrative methodological synthesis is appropriate when the aim is to integrate psychometric, conceptual, and practice-oriented literature that spans instrument development, validation, observational studies, follow-up cohorts, regional protocols, and local contextual publications. The interpretive stance was informed by applied policy analysis and by basic psychometric reasoning regarding construct validity, reliability, feasibility, and respondent burden [25, 26].

A structured search framework was used even though the review was not converted into a formal PRISMA flow study. The databases and repositories screened were PubMed/MEDLINE, Scopus, Web of Science, Embase, Cochrane Library, and the institutional repository of the *Nicolae Testemițanu* State University of Medicine and Pharmacy. The search strategy combined the disease term epilepsy with the main instrument families of interest: "QOLIE-89", "QOLIE-31", "QOLIE-31-P", "QOLIE-10", "QOLIE-48" or "QOLIE-AD-48", "Quality of Life in Epilepsy Inventory", "Epilepsy Stigma Scale", "Stigma Scale of Epilepsy", "revised epilepsy stigma scale", and "Epilepsy Self-Stigma Scale". Additional regional searches included Romanian and Moldovan terms linked to quality of life, stigma, adaptation, resocialization, rehabilitation, and adult epilepsy protocols [9, 10, 14, 16, 19].

Studies were considered eligible for the core synthesis when they met at least one of the following criteria: development of an instrument; formal psychometric validation or cross-cultural adaptation; use of a QOLIE or epilepsy-specific stigma scale in adult clinical cohorts; explicit analysis of associations between questionnaire scores and seizure burden, drug-resistant epilepsy, medication profile, psychiatric comorbidity, or stigma; or contextual regional relevance for Moldovan adult epilepsy research. Systematic reviews and meta-syntheses were used to stabilize the broader interpretive frame. Pediatric studies were excluded from the core adult synthesis, except where QOLIE-AD-48 was needed as a methodological comparator clarifying why the 48-item form should not be treated as a default adult endpoint. Non-public local files were not treated as citable evidence [1, 3, 4, 12].

Data extraction was thematic rather than numeric. Each source was read for one or more of the following analytical dimensions: target population; stigma construct or quality-of-life construct; respondent burden; study design; severity indicators used in analysis; psychometric properties; regional transferability; and practical usefulness for future Moldovan adult studies. Severity was operationalized broadly, because the adult epilepsy literature rarely relies on a single measure. Recurrent indicators included seizure frequency, uncontrolled or drug-resistant epilepsy, number of anti-seizure medications, medication adverse effects, psychiatric symptoms, epileptiform activity, employment restriction, and social participation. This broad severity lens was retained because it better reflects how the quality-of-life and stigma instruments function in real practice [1, 21, 27, 28].

Special effort was made to integrate Moldovan sources constructively rather than ceremonially. Local articles and protocol documents were not inserted merely to "nationalize" an international review. Instead, they were treated as a regional evidence layer showing how social stigma, adaptation, resocialization, and psychological rehabilitation are currently conceptualized within Moldovan clinical and academic discourse. Recent Moldovan conference and review contributions from 2024 and 2025 were therefore included as contextual sources, while stronger empirical weight was assigned to instrument-development studies, psychometric validations, multicentre cohorts, and the Romanian adult QOLIE-31-P studies that provide a more directly comparable regional measurement context [5, 20-24, 29, 30].

Because the review synthesized published and publicly accessible literature and did not involve human participants, ethics approval and informed consent were not required. The methodological purpose was practical: to convert a heterogeneous body of adult epilepsy literature into a coherent decision framework for questionnaire choice in future Moldovan studies and in an MJHS-compatible manuscript format [19, 26].

Results

Why quality of life and stigma should be synthesized together. The screened literature converged on a stable starting point: in adult epilepsy, quality of life is not an optional soft endpoint added after seizure control, but an integrated expression of how neurological, psychiatric, social, and

cultural burdens accumulate in daily life. The systematic review literature shows that quality-of-life scores are consistently damaged by uncontrolled seizures, psychiatric symptoms, adverse treatment effects, and social restriction. The stigma literature adds that some of these burdens are amplified by how the disorder is interpreted by others and by the patient. Thus, an adult with frequent seizures is not only managing a biological risk state, but also a social identity under threat. This is precisely why the quality-of-life and stigma instruments should be treated as complementary rather than competing measures [1-4].

Family context further strengthens this conclusion. Studies of adult patients and their relatives show that the epilepsy-related burden is distributed across households through emotional strain, supervision demands, role negotiation, worry, and uncertainty about future functioning. Family-centered qualitative work similarly indicates that epilepsy alters the routines and self-understandings of adult family units, not only those of the individual with seizures. These observations matter methodologically because some quality-of-life domains, such as social function, energy, or emotional well-being, are partly mediated through family ecology, while stigma can affect concealment, disclosure, and care-seeking at the household level. A narrowly clinical instrument strategy risks losing these downstream pathways [31, 32].

Historical and contemporary stigma scholarship makes the same point from another direction. Public perceptions of epilepsy have long been coloured by fear, misconceptions about competence and contagion, and the tendency to define the person through the illness. Classic work on epilepsy as a damaged self-concept anticipated the more recent distinction between public stigma and self-stigma, while contemporary analyses show that felt stigma, enacted discrimination, and internalized inferiority can coexist without being reducible to one another. This is why the label "stigma" is methodologically too broad unless it is tied to a named instrument and an explicit construct [8, 33-35].

Table 1. Epilepsy-specific quality-of-life instruments relevant to adult methodological synthesis

Instrument	Adult applicability	Best methodological use	Main advantage	Main caution
QOLIE-89 [9, 36, 37]	Yes	Deep psychometric profiling and comprehensive baseline characterization	Broad domain coverage with rich subscales	High respondent burden; less suitable for routine clinics
QOLIE-31 [10, 13, 38]	Yes	Default adult comparative and multicenter observational work	Best balance between breadth and feasibility	Less granular than the parent inventory
QOLIE-31-P [20, 21, 39, 40]	Yes	Patient-centred, real-world, longitudinal, and regional implementation studies	Adds patient weighting and preserves feasibility	Requires careful handling of local translation and scoring workflows
QOLIE-10 [11]	Yes	Rapid clinical screening and service triage	Very brief and easy to administer	Too limited for richer methodological characterization
QOLIE-AD-48 [12]	No, adolescent comparator	Contextual comparison of developmental measurement logic	Shows how severity can be captured in a broader developmental frame	Not a primary adult endpoint

Note: *QOLIE = Quality of Life in Epilepsy Inventory. Key supporting references are embedded in the first column. The 48-item instrument in the QOLIE family is predominantly QOLIE-AD-48 and is retained here only as a methodological comparator, not as a default adult outcome measure.*

QOLIE family: same lineage, different methodological roles

QOLIE-89 remains the psychometric anchor of the family. Its large domain structure allows investigators to trace the many ways epilepsy affects adult life, including cognitive complaints, emotional well-being, social isolation, seizure worry, medication effects, work and driving function, and health perceptions. This breadth makes QOLIE-89 particularly useful in studies whose purpose is scale development, responsiveness testing, comprehensive baseline phenotyping, or validation of derived measures. The trade-off is obvious and repeatedly acknowledged in practice: administration burden increases, completion is slower, and the instrument becomes less attractive for busy clinics or repeated-measure designs. In the logic of questionnaire architecture, QOLIE-89 is the instrument chosen when the objective is depth [9, 13, 36, 37].

QOLIE-31 is the most stable adult workhorse because it captures the major disease-specific domains without reproducing the full burden of the parent scale. Its development history, cross-cultural translations, repeated validation work, and use in global comparative studies make it the strongest candidate when investigators need international comparability and clinically interpretable breadth. This is particularly important for narrative synthesis, where one wants an instrument that has traveled across settings and languages without collapsing into a generic quality-of-life measure. The global comparison by Saadi et al. is especially useful in this regard, because it showed that QOLIE-31 has been used across a broad range of countries and that mean scores vary meaningfully across resource settings [10, 38, 41, 42].

QOLIE-31-P is best understood not as a trivial variant, but as a patient-weighted adult form that is especially attractive for real-world and patient-centred research. It retains a manageable length while foregrounding patient priorities more explicitly than the standard short form. This makes it valuable in longitudinal outpatient care, in refractory epilepsy services, and in studies exploring the lived salience of symptom clusters rather than merely their presence. Lithuanian psychometric work and Chinese validation studies confirm its adaptability, while Romanian studies demonstrate that it can be implemented in real Eastern European clinical prac-

tice without collapsing under logistical demands. In pragmatic research terms, QOLIE-31-P is the scale most compatible with adult follow-up studies that want both feasibility and interpretive richness [20, 21, 39, 40].

The formal role of QOLIE-10 is different. It is an efficient brief screen, useful in outpatient environments where clinicians need a fast signal of impaired epilepsy-specific well-being, but it is not a replacement for more nuanced adult measurement when the research question centres on mediation, domain profiles, or cross-cultural instrument behaviour. QOLIE-10 is at its best when the study question is operational and triage-oriented. It is at its weakest when investigators later try to extract domain-level interpretations that the instrument was never designed to provide. The adolescent QOLIE-AD-48 reinforces the same methodological lesson from the opposite direction: more items do not automatically make an instrument suitable for adults if the developmental target is wrong [11-13].

Taken together, the QOLIE family behaves less like a simple length ladder and more like a set of related instruments optimized for different analytic environments. The literature therefore supports a principle that is surprisingly often ignored in applied studies: the right instrument is not the longest or shortest one, but the one whose measurement logic matches the study's clinical setting, respondent burden tolerance, and inferential ambitions [21, 25, 38].

The adult stigma scale landscape is conceptually fragmented

The stigma literature is more fragmented than the QOLIE literature because the field is still negotiating what exactly should count as the measured object. Some instruments are closer to perceived stigma in everyday life, others to felt stigma or enacted discrimination, and the more recent self-stigma scales move inward to internalized shame, self-devaluation, and identity threat. This fragmentation is not a defect; it reflects real differences in the phenomenon. The problem arises when authors present these scales as though they were measuring the same thing with different wording. The current synthesis found that adult epilepsy stigma research is much easier to interpret when the construct is named first and the instrument second [8, 33, 35].

The Stigma Scale of Epilepsy (SSE) became one of the most visible perceived-stigma instruments after its validation in Brazil and its uptake in several clinical cohorts. The revised Epilepsy Stigma Scale associated with incident-population work is frequently used in adult epidemiological analyses and demonstrates how stigma can be treated as a variable alongside seizure burden and sociodemographic status. More recent work has expanded the field through translated adult ESS variants, including the Japanese version, and through the Epilepsy Self-Stigma Scale, which explicitly targets internalized self-stigma. The German ESSS-G further underscores that self-stigma is increasingly being treated as a distinct psychometric target rather than a hidden subset of public stigma [14-17, 43].

The Kilifi Stigma Scale for Epilepsy, although developed in Kenya and not a core Moldovan adult instrument, remains methodologically useful because it demonstrates how cultural adaptation can change not only language but also the experiential salience of stigma items. That is highly relevant for low- and middle-resource settings and for Eastern European contexts where social meanings, disclosure norms, and family expectations may differ from those embedded in original English-language instruments. In practice, this means a local team should not assume that a translated scale automatically preserves the same construct structure. Adaptation must test, not presume, equivalence [18, 25].

Table 2. Main adult stigma instruments encountered in the epilepsy literature

Instrument	Dominant construct	Typical adult use	Methodological strength	Main caution
Revised Epilepsy Stigma Scale / ESS variants [15, 43]	Felt or enacted stigma	Cross-sectional cohorts and epidemiological association studies	Works well alongside clinical severity variables	The abbreviation ESS is not fully stable across the literature
Stigma Scale of Epilepsy (SSE) [14, 44, 45]	Perceived epilepsy-related stigma	Clinical adult cohorts and quality-of-life studies	Often pairs naturally with QOLIE-31-type measures	Should not be equated with self-stigma instruments
Translated adult Epilepsy Stigma Scale forms [15]	Perceived/felt stigma	Cross-cultural adult validation work	Useful when local language equivalence is important	Translation quality must be reported explicitly
Epilepsy Self-Stigma Scale (ESSS) [16, 17]	Internalized self-stigma	Psychological and intercultural studies	Captures identity-level burden invisible to public-stigma scales	Not interchangeable with public or perceived stigma measures
Kilifi Stigma Scale for Epilepsy [18]	Perceived culturally embedded stigma	Cross-cultural comparator	Illustrates adaptation principles in non-Western settings	Not a default adult Moldovan instrument

Note: *ESS = Epilepsy Stigma Scale or revised Epilepsy Stigma Scale variants; SSE = Stigma Scale of Epilepsy; ESSS = Epilepsy Self-Stigma Scale. Key supporting references are embedded in the first column. Instrument naming in the stigma literature is inconsistent; therefore, the abbreviation and full-scale name should be expanded in the Methods and again at first use in the Results.*

Severity variables repeatedly shape both quality-of-life and stigma scores. Across the reviewed adult studies, epilepsy severity was almost never represented by one variable alone. Instead, researchers used overlapping markers of disease burden: seizure frequency, drug-resistant or uncontrolled epilepsy, polytherapy, adverse medication effects, depression, anxiety, insomnia, epileptiform activity, and social restriction. This multidimensional pattern is methodologically coherent. A patient can have infrequent seizures but a major medication burden and persistent stigma, or monthly seizures with relatively preserved emotional resilience. Quality-of-life and stigma instruments become valuable precisely because they capture the cumulative effect of these non-identical but related burdens [1, 27, 28].

The German multicentre data illustrate this well. Lower QOLIE-31 scores were associated with higher seizure fre-

quency, depressive symptoms, adverse medication effects, seizure worry, and epilepsy stigma. The Spanish refractory epilepsy cohort using QOLIE-31-P reached a similar conclusion from a service environment in which drug resistance, depression, anxiety, and sleep problems converged. These studies are methodologically important because they show that the association between worse quality of life and worse clinical status does not disappear when psychosocial variables are included; instead, clinical and psychosocial severity reinforce one another [27, 28].

The two Romanian studies make the regional signal even clearer. In the 2022 Brașov cohort, seizure frequency was negatively correlated with almost all QOLIE-31-P domains, demonstrating that a disease-specific adult measure can detect clinically meaningful variation in a real Eastern European neurology setting. The 2023 follow-up study refined the pattern: patients with epileptiform activity, polytherapy, uncontrolled seizures, and at least one seizure per month had lower QOLIE-31-P total scores at baseline and follow-up, while seizure frequency remained the strongest inverse predictor in regression analysis. This gives the regional literature something especially valuable for Moldovan planning: not only cross-sectional relevance, but proof that repeated adult measurement is feasible and informative [20, 21].

Stigma studies align with the same severity narrative. In Serbia, stigma contributed to lower health-related quality of life beyond seizure frequency and number of anti-seizure medicines. In China and Turkey, greater stigma was associated with poorer quality-of-life outcomes in adults with epilepsy. Meta-analytic evidence published in 2025 confirmed that stigmas remain common and clinically relevant, although instrument heterogeneity still limits pooled interpretation. The implication is straightforward: stigma should not be appended as an optional add-on when the real hypothesis concerns disease burden. It should be measured as part of the burden model itself [44-47].

Table 3. Selected regional and international studies informing adult epilepsy questionnaire choice

Setting and key source	Design and sample	Instrument(s)	Severity variables linked to scores	Methodological implication
Romania (Cioriceanu et al. [20])	Cross-sectional adult cohort, n=91	QOLIE-31-P	Higher seizure frequency; selected sociodemographic and clinical factors	Demonstrates regional feasibility of patient-weighted adult QOL assessment
Romania (Cioriceanu et al. [21])	Follow-up adult cohort, n=35	QOLIE-31-P	Epileptiform activity, polytherapy, uncontrolled seizures, and at least 1 seizure/month	Supports longitudinal sensitivity in real-life practice
Germany (Siebenbrodt et al. [28])	Multicentre cross-sectional study, n=476 complete QOLIE-31 datasets	QOLIE-31 plus revised Epilepsy Stigma Scale	High seizure frequency, adverse ASM effects, depressive symptoms, seizure worry, and stigma	Illustrates integrated clinical and psychosocial modelling
Spain, tertiary refractory epilepsy clinic (González-Martínez et al. [27])	Cross-sectional cohort, n=84	QOLIE-31-P	Drug-resistant epilepsy setting, depression, anxiety, and insomnia	Supports QOLIE-31-P use in high-burden tertiary cohorts
Republic of Moldova (Doțen et al. [22])	Single-case psychological rehabilitation study, n=1	Psychological rehabilitation outcome framework	Drug-resistant epilepsy, cognitive complaints, anxiety-depressive symptoms, and social isolation	Shows local relevance of rehabilitation-sensitive outcomes; evidentiary weight remains case-based

Note: *QOL = quality of life; ASM = anti-seizure medication. The table highlights anchor studies most relevant to instrument selection for adult Moldovan epilepsy research and is not intended as an exhaustive evidence inventory.*

Moldovan literature adds clinically useful context

The Moldovan evidence base is not yet dominated by large psychometric studies, but it contributes a clinically meaningful social and organizational context. The adult national clinical protocol PCN-290 is particularly important because it formalizes epilepsy care pathways using international evidence sources and explicitly frames optimization of diagnostic quality, treatment effectiveness, and patient quality of life as protocol goals. In other words, the national framework already recognises that adult epilepsy management cannot be reduced to seizure classification alone. For methodological planning, the protocol legitimizes the inclusion of quality-of-life and psychosocial endpoints in Moldovan adult studies and supports standardized reporting of clinical severity variables [19].

The 2016 Moldovan article by *Groppa et al.* places stigma and self-stigma near the center of epilepsy-related suffering. Its conceptual emphasis is highly compatible with the modern adult literature: social discrediting alters self-perception, lowers self-esteem, reduces adherence, complicates social adjustment, and worsens prognosis. Even though the paper is not a psychometric validation study, it performs an important translational role by showing that the stigma-quality-of-life relationship is already articulated in local clinical language. This matters because instrument selection is easier to justify when the construct already has local intellectual legitimacy [5].

The 2022 Moldovan papers on adaptation and resocialization deepen this contextual layer. The adaptation article frames epilepsy as a condition that creates obstacles in family life, couple relations, and wider social functioning, while also underscoring the rehabilitative value of the National Centre of Epileptology and the importance of lifestyle recommendations. The resocialization paper moves further to-

ward reintegration logic by focusing on professional participation, matrimonial status, family impact, and the place of psychotherapeutic conversations in helping patients return to ordinary social roles. These are not redundant observations. Together they suggest that Moldovan adult epilepsy research would benefit from measuring not only symptoms and seizure variables, but also how those clinical variables are translated into everyday participation [23, 24].

The 2024 Moldovan case study on psychological rehabilitation is especially valuable because it gives local evidence that psychosocial intervention can change patient-relevant domains even when seizure reduction is small. In a 39-year-old patient with drug-resistant epilepsy, ten individual counselling sessions were associated with slight improvement in memory, attention, and reaction speed, a reduction of anxiety-depressive symptoms from moderate to mild, lower hostility, greater desire for socialization, increased interest in employment, and improved treatment compliance and trust in specialists. Methodologically, this case study points toward an important future use-case for combined QOL and stigma measurement in Moldova: evaluation of rehabilitation and psychosocial care, not only pharmacological control [22].

Recent Moldovan contributions from 2025, including a narrative synthesis focused on epilepsy and social stigmatization and a conference contribution on the stigmatization phenomenon in epilepsy, suggest that local scholarship is beginning to consolidate around stigma as a core quality-of-life determinant. Even when such sources are more contextual than definitive, they still matter because they indicate what questions are becoming visible within the local research culture. For a future Moldovan adult study, that visibility is strategically important: it creates room for an instrument choice that is psychometrically serious and socially relevant at the same time [29, 30, 50].

Table 4. Recommended instrument combinations for future Moldovan adult epilepsy studies and principal supporting references

Research goal	Preferred quality-of-life tool	Preferred stigma tool	Minimal clinical covariates to report
Cross-sectional adult outpatient survey [10, 14, 15, 28, 38]	QOLIE-31	SSE or clearly defined ESS variant	Seizure frequency, seizure type, number of anti-seizure medications, adverse effects, depression/anxiety screen
Drug-resistant or tertiary-centre cohort [21, 27]	QOLIE-31-P	ESSS if internalized burden is central; SSE if perceived stigma is central	Drug resistance, seizure frequency, ASM polytherapy, adverse effects, insomnia, and psychiatric symptoms
Psychological rehabilitation or psychoeducation study [16, 22]	QOLIE-31-P	ESSS or SSE according to intervention target	Baseline stigma level, social participation, compliance, emotional symptoms, and seizure change over time
Translation and validation study [10, 15, 16, 18, 39-42]	QOLIE-31 or QOLIE-31-P	One single stigma instrument only	Reliability indices, construct validity, known-group validity, and completion burden
Rapid clinical screening in routine care [11]	QOLIE-10	Brief stigma screen or none if visit time is limited	Seizure frequency, medication burden, and brief mood assessment

Note: *QOLIE-31-P = patient-weighted Quality of Life in Epilepsy Inventory-31; SSE = Stigma Scale of Epilepsy; ESS = Epilepsy Stigma Scale or revised Epilepsy Stigma Scale variants; ESSS = Epilepsy Self-Stigma Scale; ASM = anti-seizure medication. Recommendations are synthesis-based and should be adapted to study design, translation status, and available sample size.*

Implementation issues: translation, access, and study design

A recurrent weakness in the adult literature is the dominance of cross-sectional designs. Cross-sectional studies are indispensable for mapping associations and comparing instruments, but they cannot determine whether poor quality of life precedes stigma, follows it, or co-evolves with it through recurrent seizure burden. The literature is therefore stronger on psychometric description and correlational patterning than on temporal causality. This limitation is not a reason to dismiss existing evidence; rather, it clarifies what a future Moldovan agenda should add, namely longitudinal designs, repeated measures, and more explicit modelling of clinical severity together with psychosocial mediators [1, 21, 46].

Translation and implementation deserve equal methodological attention. RAND continues to host QOLIE-89 and QOLIE-31 as public documents with scoring manuals, which lowers barriers to transparent use. At the same time, the existence of COA catalogues and licensing resources reminds investigators that instrument governance, translation procedures, and version control should be verified before local deployment, especially for short forms, patient-weighted variants, or non-English implementations. In practice, a responsible Moldovan study should document the translation pathway, forward-backward translation, cognitive debriefing, pilot burden, and basic psychometric performance rather than treating the questionnaire as a neutral import [13, 25, 48, 49]. From an implementation perspective, the literature supports a severity core set for adult Moldovan studies: seizure frequency, seizure type or focality, drug-resistant epilepsy status, number of anti-seizure medications, adverse medication effects, depression and anxiety screening, sleep problems where relevant, work status, and a clearly defined stigma measure. These variables recur often enough across international and regional studies to form a credible minimum standard, yet they remain realistic for service-based research. When this clinical core is paired with QOLIE-31 or QOLIE-31-P, the resulting design becomes both locally feasible and internationally interpretable [20, 21, 27, 28].

Discussion

This narrative methodological review supports the working hypothesis in a remarkably consistent way. Across

foundational instrument studies, psychometric validations, regional adult cohorts, and Moldovan contextual publications, lower clinical control and higher psychosocial burden are repeatedly linked to worse epilepsy-specific quality of life. What varies is not the direction of the relationship, but how investigators choose to observe it. Some focus on seizure frequency and medication profile; others foreground depression, anxiety, or stigma. The strongest adult studies, however, are not those that choose one domain and ignore the rest, but those that model quality of life as the meeting point of neurological severity and psychosocial mediation [1, 27, 28, 46].

As detailed in the Results, QOLIE-31 remains the preferred default for adult comparative research, while QOLIE-31-P better suits longitudinal or patient-centred designs, and QOLIE-10 serves screening rather than primary outcome purposes. This hierarchy follows directly from instrument design and observed use patterns, not from an ideological preference [10, 11, 20, 21, 38].

The stigma findings are equally clear but conceptually more delicate. As shown in the Results, SSE-type instruments target perceived stigma in social encounters, while ESSS-type measures capture internalized self-stigma; these constructs are overlapping but not interchangeable. The practical implication is direct: future Moldovan methods sections must name the full scale, define the target construct, and explain why that specific form of stigma was selected. That discipline would eliminate a substantial amount of interpretive noise from the local literature [14-17].

The regional and Moldovan evidence layers add more than local colour. The Romanian studies show that a disease-specific adult quality-of-life instrument can be used successfully in an Eastern European clinical environment and that repeated measurement is realistic. The Moldovan sources, in turn, show that local clinicians and researchers already view epilepsy through a psychosocial lens that includes stigma, adaptation, resocialization, and rehabilitation. This means the local research ecosystem is ready for a more formal patient-reported outcomes agenda. The necessary next step is not to discover that quality of life matters, because that is already known, but to operationalize it with methodologically coherent tools and clinically standardized covariates [5, 20-24].

One especially promising direction for Moldova is the evaluation of psychosocial and rehabilitation interventions. The 2024 local case study showed improvements in emotional stability, self-confidence, compliance, and social openness despite only slight and non-significant seizure change. This pattern mirrors a broader insight from the international literature: quality-of-life gains need not wait passively for perfect seizure control. Some may be obtained by reducing emotional distress, isolation, and self-stigma, or by improving the person's capacity to participate in work, family, and social life. For that reason, studies of psychoeducation, counselling, or multidisciplinary rehabilitation should not rely solely on crude symptom counts when selecting outcomes [22, 31, 32].

A practical Moldovan research pathway can therefore be outlined. A first phase could validate or culturally adapt one adult quality-of-life instrument, preferably QOLIE-31 or QOLIE-31-P, together with one stigma scale chosen for construct fit. A second phase could apply those instruments in a multicentre cross-sectional study reporting a minimum severity core set. A third phase could move toward follow-up design in refractory epilepsy services or psychosocial rehabilitation programs. Such sequencing would be more productive than attempting a single over-ambitious project with too many scales and too few patients. The goal is disciplined accumulation of comparable data, not decorative measurement abundance [19, 21, 25, 49].

Equally important is the way results are reported. A future Moldovan adult study should avoid the common pattern of presenting only one total quality-of-life score with minimal clinical annotation. Domain scores should be reported when sample size permits, because seizure worry, social function, emotional well-being, medication effects, and energy or cognitive complaints do not necessarily move together. The Methods section should state exactly which score version was used, how missing items were handled, whether the instrument was self-completed or interviewer-assisted, how long administration required, and whether respondents found any items culturally unclear. Such details may appear mundane, but they determine whether a study can actually be replicated or meaningfully compared with international cohorts. They are also the details most likely to matter when a questionnaire is transferred into a new linguistic and clinical environment [13, 20, 25, 40].

The literature also suggests that future Moldovan work should resist false dichotomies between neurological and psychosocial outcomes. Stigma is not merely a social afterthought, and seizure control is not the sole legitimate endpoint. A strong adult design can report both without methodological confusion: clinical variables establish the burden profile, while QOL and stigma instruments show how that burden is lived. This is particularly relevant for patients with drug-resistant epilepsy, recurrent hospital use, work exclusion, or family strain, where relatively small clinical improvements may still generate meaningful patient-reported benefit. If Moldovan studies adopt this dual-outcome logic, they will be better positioned to evaluate pharmacological management, psychosocial rehabilitation, and service organization within the same evidence framework [1, 22, 31, 32].

The review also exposes several limitations. As a narrative methodological review rather than a systematic review, this synthesis is inherently subject to selection bias in source identification and to the interpretive judgements of the authors; no pooled effect sizes can be calculated, and the breadth-versus-depth trade-off cannot be fully eliminated. A PRISMA-compliant systematic review or meta-analysis would provide a more rigorous evidential foundation but would also restrict the scope in ways incompatible with the primarily methodological aim of this work. Within the evidence base itself: first, much of the adult literature re-

mains cross-sectional, which constrains causal inference. Second, the stigma field continues to suffer from inconsistent terminology and construct overlap. Third, local Moldovan evidence is still stronger on conceptual and contextual relevance than on large-scale psychometric validation. Fourth, not all recent Moldovan 2025 items were available as complete indexed full texts at the time of synthesis, so they were used mainly as contextual rather than core empirical evidence. Finally, inclusion of QOLIE-AD-48 was deliberately limited because it is developmentally informative but not a primary adult outcome instrument. None of these limitations invalidate this synthesis, but they do define the agenda ahead [3, 29, 30, 46].

The principal strength of this review is that it integrates global psychometric literature, contemporary adult cohort data, regional Romanian measurement experience, and Moldovan clinical-social scholarship within a single methodological frame. Instead of asking only whether epilepsy worsens quality of life, it asks which questionnaire strategy best captures that worsening in adult patients and how stigma should be measured without conceptual shortcuts. That is the level at which future Moldovan research can move from general awareness to genuinely comparable evidence [5, 20-22, 38].

Conclusions

This methodological review shows that adult epilepsy burden is best assessed when epilepsy-specific quality of life and stigma are treated as complementary patient-reported outcomes rather than as interchangeable measures. For future adult studies in the Republic of Moldova, the most practical strategy is to pair QOLIE-31 or QOLIE-31-P with one stigma scale selected according to construct and to report a standardized clinical-severity core set. The added value of this synthesis is a locally adaptable measurement framework that can generate patient-reported outcome data that are clinically meaningful and internationally comparable.

Competing interests

None declared.

Authors' contributions

Conception and design of the work: AF, SG, LS, VO, VC, GL-B. Literature search and data collection: GL-B, AF. Drafting the article: AF, GL-B. Critical revision for important intellectual content: SG, LS, AF. Neurology and clinical epilepsy expertise: SG, VC. Methodology and public health expertise: LS, VO. The authors critically reviewed the work and approved the final version of the manuscript.

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Abbreviations:

ASM – anti-seizure medication; ESS – Epilepsy Stigma Scale; ESSS – Epilepsy Self-Stigma Scale; ESSS-G – German version of the Epilepsy Self-Stigma Scale; IBE – International Bureau for Epilepsy; ILAE – International League Against Epilepsy; MJHS – Moldovan Journal of Health Sciences; QOLIE – Quality of Life in Epilepsy Inventory; QOLIE-10 – Quality of Life in Epilepsy Inventory-10; QOLIE-31 – Quality of Life in Epilepsy Inventory-31; QOLIE-31-P – patient-weighted Quality of Life in Epilepsy Inventory-31; QOLIE-89 – Quality of Life in Epilepsy Inventory-89; QOLIE-AD-48 – Quality of Life in Epilepsy Inventory for Adolescents-48; SSE – Stigma Scale of Epilepsy; WHO – World Health Organization.

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