



Quality of life measure for children with Epilepsy: A psychometric evaluation of the Italian version

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ABSTRACT

Objective: To report on the Italian validation of the Child Epilepsy Quality of Life Questionnaire (CHEQOL-25), including both the child self-report and parent-proxy versions.

Methods: The validation procedure was conducted at a single Italian centre between July 2024 and July 2025, involving 252 children with epilepsy and their parents. A forward-backward translation process was carried out in line with established best-practice guidelines. Data collection included family interviews and medical chart reviews. Psychometric evaluation covered reliability and validity.

Results: All items exceeded the accepted thresholds (≥ 0.78) for both content validity and comprehensibility. The factor structure closely replicated the original five-factor model, with certain items showing stronger loadings than the original study within the *Interpersonal/Social* and *Intrapersonal/Emotional* domains in both related versions. The *Secrecy* factor showed greater variability ($h^2 = 0.06-.83$), possibly reflecting differences in parental interpretation or their sensitivity to the epilepsy concealment. Children who engaged in playful activities scored higher across most subscales, particularly in the *Interpersonal/Social* and the *Quest for Normality* domains of the self-report version. Importantly, children not receiving school support reported higher scores across several subscales, suggesting fewer perceived psychosocial challenges. Agreement between child self-reports and parent proxy-reports ranged from moderate to strong ($ICC = 0.53-.71$).

Conclusions: The Italian version of the CHEQOL-25 measure demonstrates strong psychometric properties (consistent with the original version) and reinforces the value of assessing quality of life in children with epilepsy across diverse cultural contexts.

1. Introduction

Quality-of-life (QOL) is conceptualized as a multidimensional construct encompassing domains of the human life experience including goals and expectations. 'Health-related quality-of-life' (HRQOL) is currently considered as a component of QOL that covers the person's current biopsychosocial functioning, symptoms and medication adverse effects. Although both concepts fall under the umbrella of patient-reported outcomes (PROs) they are not synonymous. Indeed, one might consider HRQOL as a depersonalized concept for measurement of

population health outcomes [1]. In the paediatric age group, PROs are conceptualised as a child's own perceptions; alternative sources (proxies) such as parents, other caregivers, teachers or healthcare providers should be applied with caution. In general, proxy reporting might be acceptable in some contexts but not in others. For example, in QOL assessment proxies tend to miss the ability of the patient to adapt and adjust one's goals and expectations through shifting internal standards and values. This phenomenon has been coined the 'disability paradox', referring to an individual's self-reported positive QOL in the face of what may appear to outsiders to be significant impairments or disabilities [2].

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Similarly, in the development of the Child Epilepsy Quality of Life Questionnaire (CHEQOL-25) the factor analyses reported from ratings by children with epilepsy, and separately by their parents on an initial 67 items questionnaire extracted from focus groups [3] revealed that children—but not their parents—identified their *quest for normality* as a major content category of QOL. Only parents identified *future concerns* as an important unique content [4].

In an epilepsy longitudinal study of parent–child dyads, overly negative or positive child and parent-proxy discrepancy responses were related to the child’s negative experiences with their peers and poor parental experiences [5]. Streiner’s (2025) comprehensive review provides an in-depth discussion of the development and psychometric foundations of the CHEQOL-25 [6].

Children with epilepsy are at higher risk of experiencing cognitive and behavioural problems, especially if seizures are drug-resistant, as in 35 % of people who develop epilepsy in their first 3 years of life [7]. Children with epilepsy may (but not invariably) experience poorer QOL than their peers on certain domains [8–10]. This is probably less due to epilepsy-specific factors than to impaired psychosocial functioning like poor peer and family support, mental health challenges, reduced academic performance, and the burden of social stigma and discrimination [11,12]. A systematic review of patient-reported outcome measures (PROMs) in children with epilepsy [13] identified 27 articles assessing the measurement properties of 11 epilepsy-specific PROMs. The psychometric quality of these tools was found to be variable, and several studies collected the questionnaires only from parents or caregivers, whereas others also included self-reports from children regarding their QOL or HRQOL. Another systematic review assessing PROMs in paediatric epilepsy mapped the content of the items of different PROMs using the International Classification of Functioning, Disability and Health, Children and Youth version (ICF-CY) framework [14]. The authors identified three generic and 13 epilepsy-specific PROMs; 10 of 16 measures utilized a biopsychosocial health approach (HRQOL) rather than a QOL approach. Content analysis showed that in 11 of 16 measures, >25 % of the items represented participation and activity components of the ICF-CY, whereas a high proportion of environment items (33 %) was found in only one epilepsy-specific measure, namely the CHEQOL-25. The authors recommended to formulate precisely what the objective of a given assessment or intervention is, and to try to understand whether the PROM approach reflects this aim [15].

Most PROM questionnaires are available exclusively in English, limiting their applicability for individuals who are not native English speakers. In particular, to date, no validated Italian HRQOL measure specifically targets paediatric epilepsy while simultaneously capturing both child and parent perspectives. Starting from these premises, we recently conducted a scoping review [16] aiming to assess which scales include both child and caregiver versions and might therefore be more suitable for collecting valid and useful QoL information in paediatric patients with epilepsy. We concluded that the CHEQOL-25 represents the most suitable instrument for assessing quality of life in children with epilepsy. CHEQOL-25 was developed by Ronen et al. [4] at the McMaster Children’s Hospital in Hamilton, Ontario in collaboration with the Canadian Pediatric Epilepsy Network (CPEN) to assess the quality of life in children and adolescents with epilepsy through both child- and parent-report forms. This tool differs from other patient-reported outcome (PRO) instruments due to its dual-informant design, its integration of both psychosocial and condition-specific domains, and its focus on the child’s perceived experience rather than solely functional outcomes.

The present report describes the Italian validation procedure of this questionnaire, conducted in a cohort of paediatric patients with epilepsy at a single Italian paediatric centre. The CHEQOL-25’s emphasis on psychosocial adaptation, emotional well-being, and perceived normality makes it particularly valuable for cross-cultural research and clinical assessment in Italy, where such patient-centred tools are limited.

2. Methods

2.1. Participants

We conducted the CHEQOL-25 Italian validation on a cohort of children affected by epilepsy of any type, and their parents, from July 2024 to July 2025 at a single tertiary paediatric epilepsy centre, specifically at Meyer Children’s Hospital, IRCCS, Florence, Italy in Italy. Inclusion criteria were as follows: age < 18 years old, epilepsy of any type, followed at Meyer Children’s Hospital IRCCS, Florence, Italy. The only general exclusion criterion was the lack of informed consent. In addition, for the child version, the participant needed to be able to understand the items and provide responses. For the parental version, inclusion relied on the parents’ willingness and/or capability to respond to more than 20 % of the questions based on their observations of their children

The study was approved by the Pediatric Ethics Committee of the Tuscany Region, Italy (Authorization CET_19/2023) and conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from parents or legal guardians, and assent was obtained from children when appropriate

2.2. Measure and procedure

Children and parents independently completed the CHEQOL-25, using either paper or digital versions depending on whether the contact was remote or in person. The scale consists of 25 items that have the format of alternative paired options of forced responses [17]. Proxy raters were asked to respond the way they thought their child would answer the questions. Each item is scored on a scale of 1 to 4. A higher score reflects a better perception of the child’s QOL. The scale itself was developed by interviewing children and their parents separately, using a focus group format [3]. Factor analysis suggested a 5-factor structure, each consisting of five items [4]. The subscales are named: *Interpersonal/Social*, *Present Concerns*, *Intrapersonal/Emotional*, *Secrecy*, *Quest for Normality* (child only) and *Future Concerns* (parent only).

Since the questionnaire is under copyright, a License Agreement was signed between the Host University of Florence, Italy and the publisher, in January 2024. The original English version was translated into Italian using a forward–backward translation procedure in accordance with best practice guidelines for cross-cultural instrument adaptation [18]. First, two bilingual psychologists independently translated the items from English into Italian. These translations were compared, and discrepancies were resolved through discussion to develop a single preliminary Italian version. This version was then back-translated into English by two independent bilingual translators unfamiliar with the original instrument. The back-translation was reviewed by four individuals (two psychologists and two epilepsy professionals) in a focus group format. They evaluated: a. the comprehensibility of the content of the statements for children; b. whether all the item content and wording were applicable to children with epilepsy in the Italian language and culture; and c. concerns about the item format. Minor adjustments were made to preserve meaning appropriateness in an Italian-speaking context. Finally, the Italian version of the CHEQOL-25 was administered to children with epilepsy ($n = 11$), parents of children with epilepsy ($n = 14$), and specialists in epilepsy ($n = 18$) to assess item comprehensibility. Specialists were also asked to rate the relevance (indicator of content validity) of each item.

Data collection was completed by healthcare professionals by interviewing the patient and the parents and by reviewing the medical charts. Specifically, we collected information on age at evaluation, age at seizure onset, epilepsy syndrome and aetiology [19], resistance to antiseizure medication (ASM) [20], cognitive performances [21], whether they had undergone surgical treatment or were on ASM alone. In addition, we collected data on non-epilepsy-related variables, including: the educational level of the child and parents, school support

received by the child, ongoing rehabilitation, recreational activities, parents' occupation, housing situation, socioeconomic status, and place of residence.

2.3. Statistical analysis

Content validity and Comprehensibility. Ratings were done on a 4-point Likert scale (1 = very irrelevant/very unclear; 2 = irrelevant/unclear; 3 = relevant/clear; 4 = very relevant/very clear). For each item, indices were calculated for comprehensibility (I-CI) and content validity (I-CVI) by dividing the number of respondents who rated the item as 'relevant/comprehensible' by the total number of respondents. Item indices < 0.78 are considered inadequate and require further analysis. Indices between 0.80 and 0.89 were considered acceptable and from 0.90 as excellent [22].

Missing data analysis. Prior to analysis, data were screened for missing responses. The average percentage of missing data was 1.6 % across items for the child version (Range: 0–4.6 %) and 1.9 % (range: 0.4 % – 4.1 %) across items for the parent version. Given the minimal level of missingness, data were handled using listwise deletion, consistent with best practices for datasets with less than 5 % missing data.

Preliminary data screening. Floor and ceiling effects were examined according to the criteria of Terwee et al., [23] which define substantial effects when more than 15 % of respondents achieve the minimum or maximum possible score. For the CHEQOL-25 total mean score parent version, only 0.4 % of participants scored at the lowest or highest observed value, indicating no evidence of floor or ceiling effects and an adequate range of score variability. We examined floor/ceiling effects at the scale level for the child version. No participants obtained the lowest (1.00) or highest (4.00) possible score (floor = 0.0 %, ceiling = 0.0 % of 149 valid cases), indicating absence of floor/ceiling effects.

Factorial Validity and Item Analysis. To evaluate the factorial validity of the child and adult versions of the questionnaire, we conducted confirmatory item response theory (IRT) analyses using the graded response model (GRM) [24]. This model is appropriate for ordered categorical (Likert-type) response data and allows for the estimation of item discrimination (slope) and category threshold (location) parameters across multiple latent dimensions. A correlated five-factor structure was specified for each version based on theoretical expectations and prior exploratory work [4].

Analyses were conducted in the "mirt" package [25] in R. We estimated multidimensional models using the Metropolis–Hastings Robbins–Monro (MHRM) algorithm because it provides stable estimation and standard errors for high-dimensional polytomous models and is recommended for complex latent structures [26]. Model solutions provided item-level parameter estimates (discrimination, thresholds), standardized factor loadings, communalities, and inter-factor correlations.

We compared two polytomous IRT families with identical five-factor structures: the graded response model (GRM) and the generalized partial credit model (GPCM). The GRM provided the superior fit (higher log-likelihood; lower AIC/BIC) and its cumulative threshold parameterization aligns with the ordered Likert response process of CHEQOL-25 items. We therefore retained the multidimensional GRM for all reported item- and test-level results.

Following graded response model (GRM) estimation, expected posteriori (EAP) ability estimates were computed for each latent dimension. The EAP scores were highly correlated with summed raw scores for both the parent ($r = 0.96$) and child ($r = 0.93$) versions, indicating near-linear correspondence between the two metrics. Given this strong association, and to maintain comparability with prior CHEQOL validation studies and clinical interpretability of mean raw scores, subsequent analyses were conducted using raw mean scores. This approach ensures that findings remain consistent with established CHEQOL reporting conventions while acknowledging that the underlying measurement structure was verified through the IRT model. Unlike classical test theory,

which assumes equal item contributions, IRT allows for the estimation of item-specific discrimination and threshold parameters, thereby yielding more precise measurement information [27].

Inter-item Reliability was assessed using both Cronbach's alpha (α) [28] and McDonald's omega (ω) [29], as omega provides a less biased estimate of reliability in the presence of multidimensionality and heterogeneous factor loadings. Following guidelines for scale evaluation, values ≥ 0.70 were considered acceptable [30].

Construct Validity. T-tests (to compare two independent groups) and one-way ANOVAs (to compare more than two independent groups) with Bonferroni's post hoc test (i.e., multiple comparisons between every combination of pairs) were conducted. As measures of effect size, Cohen's d was used for t -test (values from 0.2 to 0.5 are indicators of a small effect, values from 0.5 to 0.8 represent a medium effect, and values from 0.8 a large effect) and the partial eta squared (η^2) for ANOVAs (values lower than 0.06 suggest a small effect, values from 0.06 to 0.14 a medium effect, values from 0.14 a large effect).

Agreement between Raters (Reliability). Agreement between child self-reports and parent proxy-reports was evaluated using a two-way mixed-effects intraclass correlation coefficient (ICC), based on an absolute agreement definition [31]. This method was selected because both child and parent reports were treated as fixed raters assessing the same target (the child's QOL), and absolute agreement was the parameter of interest rather than consistency of ranking. ICC values below 0.50 were interpreted as poor, between 0.50–.75 as moderate, between 0.75–.90 as good, and above 0.90 as excellent agreement. Additionally, the paired t -test was conducted to compare scale scores using Cohen's d as a measure of effect size (see below the values cut-offs).

3. Results

3.1. Content validity and comprehensibility.

The group of experts ($n = 18$) consisted of 16 physicians and 2 psychologists with ages ranging from 25 to 52 years ($M = 30.29$, $SD = 6.01$) and reported a mean of 4.76 ($SD = 6.05$) years of experience. The group of children ($n = 11$) consisted of 36 % females and ages ranged from 11 to 18 years ($M = 16.55$, $SD = 2.11$). The group of parents ($n = 14$) consisted of 64 % females and ages ranged from 43 to 62 years ($M = 51.71$, $SD = 5.26$).

Overall, indices of comprehensibility (I-CI) and content validity (I-CVI) were equal or higher the expected cutoff of 0.78. The only item that received a poor evaluation in comprehensibility from all groups was Item 2 "*Alcuni bambini/ragazzi con l'epilessia pensano di non essere bravi a fare le cose in confronto agli altri bambini/ragazzi ma altri bambini/ragazzi con l'epilessia pensando di essere bravi a fare le cose come gli altri bambini/ragazzi*" (Some kids with epilepsy think they are not as good at things as other kids but other kids with epilepsy think they are just as good at things as other kids are). Individual interviews revealed that the Italian term "*cose*" (things) was deemed too vague. However, to maintain the same meaning of the original item, it was not possible to change the wording. Thus, we adopted a conservative approach, and we maintained all the items (Supplementary Table 1).

Item-level CVI values were averaged to yield mean content validity indices a tpta; pf 700 fam Interpersonal/Social ($M = 0.87$, $SD = 0.16$), Present Concerns ($M = 0.86$, $SD = 0.07$), Intrapersonal/Emotion ($M = 0.92$, $SD = 0.05$), Secrecy ($M = 0.90$, $SD = 0.04$), Normality ($M = 0.91$, $SD = 0.06$), and Future Concerns ($M = 0.84$, $SD = 0.11$). The overall mean CVI across domains was 0.88 ($SD = 0.08$), indicating excellent content validity (Table 1). The detailed item-level I-CVI values are presented in Supplementary Table 2.

3.2. Sample descriptives

A total of 700 families were contacted, of which 252 consented to participate in the study. Questionnaires were later unavailable for nine

Table 1

Mean Item Content Validity Indices (CVI) for CHEQOL-25 Domains.

Domain	Items Included	Mean I-CVI	SD
Interpersonal/Social	1–5	0.87	0.16
Present Concerns	6–10	0.86	0.07
Intrapersonal/Emotion	11–15, 16–20	0.92	0.05
Secrecy	16–20, 21–25	0.90	0.04
Normality	21–25	0.91	0.06
Future Concerns	11P–15P	0.84	0.11
Overall Mean	—	0.88	0.08

pairs due to a lack of willingness to submit responses ($n = 3$) or the provision of fewer than 20 % of responses ($n = 6$). Additionally, the child version of the CHEQOL-25 from 100 patients could not be obtained because of cognitive challenges ($n = 55$), and behavioural challenges ($n = 13$) which prevented them from understanding or responding to the questions, or parental disapproval ($n = 32$), as some parents expressed concerns about their children's reactions to the questions or considered them too young to participate. Parental decisions were not influenced by the examiner. The final sample comprised 152 children and 243 parents. Detailed sociodemographic and clinical information are presented in [Supplementary Tables 3–5](#).

The final child sample included 152 individuals with a mean age of seizure onset of 53.35 ± 45.95 months.

The majority of the young people with epilepsy presented with lesional focal epilepsy ($n = 118$), followed by developmental and epileptic encephalopathy ($n = 50$), self-limited focal epilepsy ($n = 34$), and nonlesional focal epilepsy ($n = 21$), with fewer individuals with idiopathic ($n = 17$) or genetic generalized epilepsy ($n = 12$). The most common aetiologies were structural ($n = 116$), unknown ($n = 103$), and genetic ($n = 48$). Most children demonstrated a normal cognitive level ($n = 163$), while others showed mild ($n = 46$), moderate ($n = 34$), or severe ($n = 9$) intellectual impairment. In terms of treatment, most received ASM polytherapy ($n = 126$) or monotherapy ($n = 96$), with smaller groups undergoing surgery ($n = 68$), ASM withdrawal ($n = 15$), or no ASM treatment ($n = 15$). Regarding response to ASM, 150 children were drug-resistant, 87 drug-responsive, and 15 had never received ASM.

Among families, most first (49 %) and second (44.5 %) parents had high-school education, followed by university degrees (32–23 %), and only a small number held postgraduate qualifications (3–4 %). The majority of parents were in long-term employment (68–76 %), while unemployment rates were 18 % for first and 7 % for second parents. Most families were married (76 %), middle class (53 %), and homeowners (65 %), primarily residing in Central Italy (66 %). About 42 % of families received social welfare, and 35 % of children received school support, while 79 % participated in rehabilitation programs and 25 % in sports or recreational activities.

The parent sample ($n = 243$) had children with a mean age of 11.30 ± 3.58 years (range = 4–17.9), with a slight female predominance (55.1 %). Most children attended primary (43.6 %) or secondary school (30.1 %). Parents showed similar educational and occupational distributions as the overall family sample, with high-school (48–46 %) and university education (31–27 %) most common, and long-term employment (66–78 %) predominant. Most families were married (73 %), middle class (51 %), and homeowners (61 %), residing mainly in Central Italy (58 %). Over half received social welfare (55 %) and school support (50 %), while 84.7 % of children were engaged in rehabilitation programs and 30 % participated in play or sports activities. The demographic and clinical profile of our Italian sample was broadly consistent with those reported in the English CHEQOL-25 validation study. We conducted independent-samples t-tests between the original English sample ($n = 81$) and our Italian cohort ($n = 152$). Children in the Italian sample were significantly older at assessment ($p = 0.001$, $d = 0.43$) and had an earlier age of epilepsy onset ($p < 0.001$, $d = 0.58$).

3.3. Factorial validity

A confirmatory five-factor graded response model was estimated in *mirt* using the Metropolis–Hastings Robbins–Monro (MHRM) algorithm with standard errors.

The five-factor for the proxy version correlated graded response model demonstrated acceptable overall fit to the data, $M2(265) = 791.08$, $p < 0.001$, RMSEA = 0.091 (90 % CI [0.083, 0.098]), SRMSR = 0.10, TLI = 0.90, CFI = 0.91, indicating an adequate though slightly suboptimal fit consistent with complex multidimensional patient-reported outcome measures. A five-factor correlated graded response model was estimated for the child version of the CHEQOL-25 using quasi–Monte Carlo integration to accommodate the high-dimensional structure. The model demonstrated suboptimal but interpretable global fit, $M2(215) = 487.14$, $p < 0.001$, RMSEA = 0.091 (90 % CI [0.080, 0.102]), SRMSR = 0.111, TLI = 0.69, CFI = 0.74. Although incremental fit indices were below conventional thresholds, the RMSEA indicated an adequate approximation error given the model's multidimensional complexity and ordinal item structure. Taken together, these indices suggest a partially adequate representation of the hypothesized multidimensional construct in the child sample.

Referring to the Child Self-reported Version ([Table 2](#)), across factors, the solution accounted for 52.4 % of total item variance. Items showed the expected structure: Interpersonal/Social loadings ranged from 0.72 to 0.88 with communalities 0.52–.78; Present Concerns loadings ranged from 0.60 to 0.75 with communalities 0.36–.56; Intrapersonal/Emotional loadings ranged from 0.44 to 0.94 with communalities

Table 2

Item discrimination, category thresholds, factor loading, and communality from a five-factor graded response model of the Quality-of-Life Measure for Children with Epilepsy (CHEQOL-25) – Child version.

Item	a	b_1	b_2	b_3	Factor Loading (λ)	h^2
1. Playful	1.94	−1.96	−0.93	−0.22	F1 0.75	0.57
2. Good at things	1.78	−1.80	−0.63	0.00	F1 0.72	0.52
3. Have Friends	2.07	−1.56	−0.80	−0.29	F1 0.77	0.60
4. Treated Differently	2.18	−1.38	−0.50	−0.06	F1 0.79	0.62
5. Picked on	3.19	−1.21	−0.74	−0.10	F1 0.88	0.78
6. Think about epilepsy	1.47	−1.56	−0.52	0.34	F2 0.65	0.43
7. Parents worry	1.73	−0.49	0.36	0.72	F2 0.71	0.51
8. Camp and activities	1.93	−1.60	−1.02	−0.45	F2 0.75	0.56
9. Forget Medications	1.28	−0.44	0.58	1.33	F2 0.60	0.36
10. Getting hurt	1.57	−0.82	−0.22	0.62	F2 0.68	0.46
11. Upset easily	3.61	−0.71	0.11	0.54	F3 0.91	0.82
12. Paying attention	1.46	−0.79	0.07	0.66	F3 0.65	0.43
13. Get angry	4.57	−0.79	−0.08	0.38	F3 0.94	0.88
14. Remember school	1.46	−1.17	−0.04	0.84	F3 0.65	0.42
15. Seizure Medication	0.83	−1.67	−0.38	0.86	F3 0.44	0.19
16. Telling people about epilepsy(R)	0.66	−2.05	−0.54	1.25	F4 0.36	0.13
17. Afraid friends find out	1.93	−1.38	−0.82	−0.06	F4 0.75	0.56
18. Feel safe away from home (R)	1.08	−1.72	−0.41	0.56	F4 0.54	0.29
19. Embarrassed epilepsy	2.64	−1.40	−0.69	−0.14	F4 0.84	0.71
20. Friends afraid of them	2.36	−1.99	−1.27	−0.64	F4 0.81	0.66
21. Treated the same as sibling(R)	1.21	−1.88	−0.97	−0.16	F5 0.58	0.34
22. Live normal life after seizures	2.83	−1.39	−1.11	−0.38	F5 0.86	0.73
23. Teachers treat same (R)	1.49	−1.57	−0.91	−0.25	F5 0.66	0.43
24. Epilepsy slows down(R)	2.31	−1.59	−0.86	−0.14	F5 0.80	0.65
25. Comfortable at school (R)	1.54	−1.97	−0.99	−0.18	F5 0.67	0.45

0.19–.88; Secrecy loadings ranged from 0.36 to 0.84 with communalities 0.13–.71; and Normality loadings ranged from 0.58 to 0.86 with communalities 0.34–.73. Latent factors were moderately to strongly correlated ($r_s = 0.43$ –.91), indicating substantial shared variance across the five dimensions.

A confirmatory five-factor graded response model for the proxy version was fit in *mirt* using MHRM estimation with standard errors (Table 3). The five factors accounted for 53.5 % of total item variance. Items showed the expected simple structure: Interpersonal/Social loadings ranged from 0.69 to 0.84 with communalities $h^2 = 0.48$ –.71; Present Concerns loadings ranged from 0.59 to 0.78, $h^2 = 0.35$ –.62; Intrapersonal/Emotional loadings ranged from 0.75 to 0.89, $h^2 = 0.56$ –.79; Normality loadings ranged from 0.54 to 0.78, $h^2 = 0.29$ –.60; and Secrecy loadings ranged from 0.24 to 0.91, $h^2 = 0.06$ –.83. Category thresholds were ordered as expected, indicating increasing response

Table 3

Item discrimination (a), category thresholds, factor loading, and communality from a five-factor graded response model of the Quality-of-Life Measure for Children with Epilepsy (CHEQOL-25)- Parent version.

Item	a	b ₁	b ₂	b ₃	Factor Loading (λ)	h ²
1. Kids won't play with them	2.05	−1.62	−0.24	0.44	F1 0.77	0.59
2. Not as good as others	1.64	−1.55	−0.20	0.54	F1 0.69	0.48
3. Not many friends	2.05	−1.14	−0.26	0.27	F1 0.77	0.59
4. Treated differently	2.63	−1.10	−0.13	0.48	F1 0.84	0.71
5. Picked on	2.15	−1.51	−0.51	0.30	F1 0.79	0.62
6. Must think about epilepsy first	1.93	−1.09	−0.43	0.45	F2 0.75	0.56
7. Parents worried they'll get hurt	2.11	−0.43	0.42	1.01	F2 0.78	0.60
8. Can't go to camp/activities	1.24	−1.85	−0.84	0.09	F2 0.59	0.35
9. Worry about forgetting medicine	1.26	−0.52	0.54	1.47	F2 0.60	0.35
10. Worry about getting hurt in seizure	2.15	−0.78	0.07	0.66	F2 0.78	0.62
11. Scared about the future	2.04	−1.21	−0.20	0.70	F3 0.77	0.59
12. Worry won't be able to drive	2.67	−0.60	0.04	0.71	F3 0.84	0.71
13. Unsure about future work	3.32	−0.81	−0.10	0.32	F3 0.89	0.79
14. Unsure how they'll manage as teens	2.65	−0.96	−0.20	0.47	F3 0.84	0.71
15. Afraid others won't treat them well	1.92	−1.70	−0.64	0.26	F3 0.75	0.56
16. Get upset easily	2.07	−0.50	0.33	0.84	F4 0.77	0.60
17. Trouble paying attention	2.13	−0.31	0.65	1.34	F4 0.78	0.61
18. Get angry easily	1.66	−0.75	0.14	1.08	F4 0.70	0.49
19. Trouble remembering at school	1.47	−1.03	0.09	0.82	F4 0.65	0.43
20. Think epilepsy won't go away	1.09	−1.86	−0.48	0.88	F4 0.54	0.29
21. Feel OK telling others (R)	1.28	−1.07	0.07	1.40	F5 0.60	0.36
22. Afraid friends will find out	2.82	−1.39	−0.32	0.35	F5 0.86	0.73
23. Feel embarrassed about epilepsy	3.80	−1.11	−0.20	0.47	F5 0.91	0.83
24. Feel safe with friends (R)	0.43	−3.21	0.09	3.79	F5 0.24	0.06
25. Afraid no one will know what to do during seizure	0.82	−1.64	0.51	2.08	F5 0.43	0.19

Note. Values are from a correlated five-factor graded response model estimated with MHRM in *mirt*. Column a is the item discrimination for the loading factor in a five-factor model; b_1 – b_3 are category thresholds on the latent-trait metric; h^2 is the item communality. F1 = Interpersonal/Social, F2=Present Concerns; F3 = Future Concerns; F4 = Intrapersonal/emotion; F5= Secrecy.

category severity. Latent factors were moderately to strongly correlated ($r_s = 0.24$ –.79), suggesting substantial shared variance among factors.

Notes. Items are abbreviated, R represents reverse coded (see Ronen et al. [4] for full set of items). Values are from a correlated five-factor graded response model estimated with MHRM in *mirt*. Column a is the item discrimination for the loading factor in a five-factor model; b_1 – b_3 are category thresholds on the latent-trait metric; h^2 is the item communality. F1 = interpersonal/social, F2= Present Concerns, F3 = Intrapersonal/Emotional, F4 = Intrapersonal/Emotion, F4= Secrecy, F5= Normality.

3.4. Reliability

Internal consistency was acceptable-to-strong for the child version: *Interpersonal/Social* ($\omega = 0.80$, $\alpha = 0.80$), *Present Concerns* ($\omega = 0.70$, $\alpha = 0.69$), *Intrapersonal/Emotional* ($\omega = 0.77$, $\alpha = 0.76$), *Secrecy* ($\omega = 0.65$, $\alpha = 0.63$), and *Normality* ($\omega = 0.70$, $\alpha = 0.69$). For the proxy version, reliability was acceptable to strong: *Interpersonal/Social* ($\omega = 0.81$, $\alpha = 0.81$), *Present Concerns* ($\omega = 0.75$, $\alpha = 0.74$), *Intrapersonal/Emotional* ($\omega = 0.72$, $\alpha = 0.74$), *Secrecy* ($\omega = 0.62$, $\alpha = 0.62$), *Future concern* ($\omega = 0.85$, $\alpha = 0.84$).

3.5. Construct validity

In both parent proxy-report and child self-report, t-tests revealed better scores in all the subscales for children engaged in playful and sports activities compared with those who were not, except for *Present Concerns*, and *Secrecy* on the parent version. The strongest difference was on *Interpersonal/social scale* (0.79) of the child version followed by *Quest for Normality* (0.67) of the same version.

Apart from the *Secrecy* subscale of the proxy version, the ANOVAs showed higher scores for all the subscales between children not receiving any school support compared to those receiving full-time or part-time support (see [Supplementary Tables 6,7](#)).

3.6. Rater agreement

The sample included 129 dyads of child and parent, and agreement between them was calculated. The ICC ranged from 0.53 to 0.71, indicating moderate agreement. Comparing the scores, parents rated the QOL of the child slightly higher ($d = 0.32$) than did the children themselves on the Interpersonal/Social scale. On the other hand, the moderate difference ($d = 0.75$) between parent proxy-report and child self-report on Secrecy suggested that children's rating was better than the parent's rating. No differences were observed on Present Concerns and Intrapersonal/Emotion ([Supplementary Table 8](#)).

4. Discussion

In this report, we validated the Italian version of the CHEQOL-25 using a cohort of 152 children and 243 parents recruited at a single tertiary level paediatric epilepsy clinical and university centre. The study sample encompassed different age groups, epilepsy syndromes, aetiologies, and response to medical and surgical treatments. Children are diagnosed and followed longitudinally across different care settings, ranging from those with newly onset or medication-responsive seizures seen in outpatient clinics, to those with more complex or refractory seizures managed in inpatient units. In addition to serving children in the region, approximately 40 % of children are referred from other regions of Italy. This extends the generalizability of our results by involving a real-world paediatric population with epilepsy in both research and clinical settings.

In addition, we collected information on socio-economic factors thus helping us analyse the “contextual effect” of epilepsy in general.

Evaluation of the CHEQOL-25 by content experts and children with epilepsy and their parents led to evidence of the content and face

validity of a 25-item version of the tool. The only exception was item 2, “*Alcuni bambini/ragazzi con l’epilessia pensano di non essere bravi a fare le cose in confronto agli altri bambini/ragazzi ma altri bambini/ragazzi con l’epilessia pensando di essere bravi a fare le cose come gli altri bambini/ragazzi*” (Some kids with epilepsy think they are not as good at things as other kids but other kids with epilepsy think they are just as good at things as other kids are), which was indicated for its use of the vague term “things” in all three groups. Despite the ambiguity, it was decided to retain the item in its original formulation to preserve semantic equivalence with the original version.

The factor structure replicated Ronen’s five-factor model [4] with some items more closely related to each other, particularly within the Interpersonal/Social and Intrapersonal/Emotional dimensions for both versions. This result is consistent with the idea that interventions aimed at promoting social integration (e.g., educational support or anti-stigma interventions) may have positive effects on emotional well-being [32]. Overall, the *Secrecy* showed a higher variability ($h^2 = 0.06-.83$), possibly indicating differing parental interpretations or sensitivities toward this domain. In the original version, the authors observed that the *Secrecy* subscale had a higher variability than other subscales, explaining that the perception of the need to hide epilepsy varies greatly between families, influenced by cultural and personal factors. The modest correlation between the subscales and the varied correlations observed indicate that these measures are indeed multidimensional constructs [4].

From the point of view of reliability and construct validity, the Italian version of the CHEQOL-25 questionnaire exhibits, in general, good characteristics. The internal consistency confirmed the trend that was observed in the previous analyses, with a slight improvement for two subscales. The higher coefficients in the parent version for *Present Concerns* ($\alpha = 0.74$ vs 0.64) may reflect improved cultural adaptation or refinements in item interpretation. Like the original version, the lowest internal consistency was noted in the *Secrecy* subscale, ($\alpha = 0.62$ vs 0.70), in line with previous observations that parental sensitivity to this domain varies considerably across families and cultural contexts [4].

Although concurrent and discriminant validity could not be directly examined due to the lack of other validated Italian epilepsy-specific quality-of-life instruments, construct validity was indirectly supported through theoretically consistent associations between CHEQOL-25 subscales and relevant contextual variables such as school support and engagement in playful activities, aligning with prior evidence on paediatric epilepsy quality of life and parent proxy measures [5,33]. Children engaged in playful, and sports activities reported less difficulties in most subscales, particularly in the *Interpersonal/Social* and *Quest for Normality* domains in the Child version, showing better social adaptation and self-perception [34]. Similarly, children not receiving school support had better scores on most subscales, indicating fewer psychosocial difficulties. The absence of differences in *Present Concerns* and *Secrecy* on the parent version may reflect limited parental insight into the child’s internal experiences. In this regard, Ronen and colleagues [3] observed that there is generally good agreement between parent and child on observable aspects (physical functioning, activities), but poor agreement on internal/emotional aspects, such as feelings, intimate experiences, and secrecy. Parents therefore don’t always recognize internal emotional strain and concerns since many of these feelings are not very visible.

The level of agreement between child self-reported and parent proxy-reported was moderate ($ICC = 0.53-.71$), indicating a generally consistent perception of several aspects of the child’s quality of life (QOL) across respondents. As in the original validation by Ronen et al. [4] and subsequent adaptations (e.g., Malaysian-Chinese [35], Vietnamese [36], Thai [37] Hong Kong-Chinese [38], Kenyan [39], and Serbian [40] versions), the level of agreement between child and parent reports was moderate overall, with stronger agreement in observable domains and higher disagreement in internalized or subjective domains. In the Italian version parents assessed their child’s interpersonal and

social functioning slightly better than children themselves ($d = 0.32$), a pattern frequently observed in paediatric QOL research, where parents may overestimate social adjustment. Conversely, a moderate effect ($d = 0.75$) on the *Secrecy* subscale suggests that children perceive themselves as more reserved than their parents recognize, suggesting less parental recognition of their children’s internalized experiences. This pronounced difference observed in the *Secrecy* subscale reflects results from the Malaysian-Chinese [35] and Serbian [40] validations, where parental reports underestimated children’s tendency to hide their condition. No significant differences were observed in the *Present Concerns* and *Intrapersonal/Emotional* subscales, suggesting greater alignment between child and parent perspectives in these areas. These aspects compared with some earlier studies, such as the Vietnamese [36] validation where intrapersonal concerns showed lower agreement.

4.1. Limitations of the study

Our study is limited by the fact that the child’s and parental questionnaires were available together only in 129 out of 243 families. While cognitive and behavioural barriers to patient recruitment are to be expected in a cohort of children with epilepsy, it is noteworthy that several parents refused permission for their children to complete the questionnaires, fearing that the questions about well-being might trigger negative emotional reactions. This reluctance provides indirect demonstration that perceived stigma and psychosocial difficulties remain prevalent within families of this population. On the other side, the evidence of medium-to-strong agreement between parents and children in the 129 families for which both questionnaires were available strengthens our findings.

Future studies could evaluate alternative Italian formulations of item 2 and/or assess whether the linguistic ambiguity mentioned influences the psychometrics results. Although this study confirmed the five-factor structure of the CHEQOL-25 based on the original English factor analysis, we did not conduct a confirmatory factor analysis (CFA) to compare alternative dimensional structures (e.g., unidimensional, hierarchical, or bifactor models). Future research with larger Italian samples should evaluate and compare competing CFA models to more rigorously determine the optimal latent structure before item calibration within an IRT framework. The nature of the *Secrecy* subscale, which showed slightly less stable psychometric properties in both versions, although in line with current literature, could be further explored. Further exploration of construct validity through correlational and regression analyses would provide valuable insights into how quality of life scores are related to sociodemographic and clinical characteristics. Due to the limited sample size and the study’s primary focus on psychometrics, these analyses were not included in this article but could be integrated into a follow-up study designed to examine predictors of children’s and parents’ quality of life scores (e.g., parent and peer social support, mental health, cognitive level, seizure and family characteristics). Future work should examine associations and independent predictors of CHEQOL-25 scores and compare the models with the results of other national validation studies. Furthermore, participation in playful or sporting activities and access to school support were measured cross-sectionally and may be influenced by many factors such as severity of epilepsy, cognitive resources, or family support. Further longitudinal studies will be required to further clarify any potential directionality of these associations [10]. Similarly, qualitative investigations might provide further insights into how children perceive their experiences in sports [33,34] and school, particularly in relation to feelings of normalcy and social inclusion. Future research should also incorporate longitudinal designs and multi-measure validation approaches to assess the instrument’s reliability and construct validity more comprehensively across time and related domains.

5. Conclusion

This study validates the Italian version of the CHEQOL-25 questionnaire in a real-world paediatric population with epilepsy, supporting its use in both research and clinical settings. The Italian CHEQOL-25 demonstrates strong psychometric properties, consistent with the original version, and underscores the importance of assessing quality of life in children with epilepsy across diverse cultural contexts.

6. Data statement

The use of the Quality-of-Life Questionnaire in Children with Epilepsy, authored by Dr. Gabriel Ronen et al., was made under license from McMaster University, Hamilton, Canada.

Researchers who would like to access the Italian translation of the questionnaire must submit a request form through the website link: <https://research.mcmaster.ca/industry-investors/technologies-available-for-licensing/request-for-license/>.

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CRediT authorship contribution statement

Carlotta Tagliaferro: Writing – original draft, Formal analysis, Conceptualization. **Elena Cavallini:** Supervision, Data curation. **Pietro Cappelletto:** Investigation, Data curation. **Chloe Lau:** Formal analysis, Writing – review & editing. **Martina Preti:** Investigation, Formal analysis. **Claudia Marino:** Investigation, Data curation. **Simona Pellacani:** Supervision, Investigation. **Gabriel M. Ronen:** . **Francesca Chiesi:** Formal analysis, Conceptualization. **Carmen Barba:** Writing – original draft, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2025.110857>.

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