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Review

Reappraising self-report and proxy-report measures for assessing health-related quality of life in pediatric epilepsy: A scoping review

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ABSTRACT

This scoping review aimed to evaluate specific measures of health-related quality of life (HRQoL) in children with epilepsy including patient- and proxy-reports, to determine their suitability for use in the clinical setting. We searched PubMed, Web of Science, PsycINFO Scopus for studies on the childhood epilepsy questionnaires identified as having better measurement properties and/or including proxy and parent reports. Then, we selected the studies that analyzed the agreement between child and caregiver ratings. We identified five scales i.e., the QoLPES, the HARCES, the PedsQL-Epilepsy Module, and the CHEQoL-25 and observed a moderate to high agreement between the proxy-reports and child self-reports. The CHEQoL-25 appears to be preferable due to its well-documented psychometric properties, high usability, and adequate agreement between proxy and child versions. This scoping review highlights the need to use PROMs that allow to gather information from both the caregiver and child, with the CHEQoL-25 being the best candidate for assessing HRQol in children with epilepsy.

1. Introduction

A global burden of disease study ranked epilepsy as the fifth most burdensome neurological disease in 2016, accounting for more than 13 million disability-adjusted life-years worldwide [1]. Indeed, epilepsy has neurological, cognitive, psychological, and social consequences that impact the patient's quality of life (QoL) well beyond the occurrence of seizures [2,3].

Calman [4] described QoL as the gap, at a particular point in time, between an individual's hopes and expectations and that individual's current experiences. The World Health Organization [5] expanded this idea and defined QoL as the perception of one's position in life in the context of the culture and value systems in which one lives and in relation to one's goals, expectations, standards and concerns. In the context of healthcare, the concept of health-related quality of life (HRQoL) is widely used but it is difficult to find a common definition (for detailed reviews on this issue see: [6–9]). In general terms, we can refer to HRQoL as the impact of a health condition on one's QoL. That is, a health condition may be the cause of the above-mentioned gap [4], and an illness may be subjectively perceived as a strong determinant of the distance between one's current position in life and one's goals and desires. This is especially true when the disease affects emotional, cognitive, and physical functioning by impeding common activities and participation in life situations.

However, the concepts of QoL and HRQoL have been continually redefined, which has led to countering the idea that functioning and clinical symptoms are surrogates for overall QoL. On the contrary, a fundamental aspect of QoL is the ability to adapt to new life circumstances. As such, it includes hopes, expectations and personal goals that are not reflected in the assessment of current functioning and symptoms. A case in point is the "disability paradox" [10] which refers to an individual's self-reported positive QoL despite significant disabilities or poor functioning.

Epilepsy affects all ages with incidence peaking in the youngest and the elderly [11]. Indeed, as health perspectives shift to long-term care and treatment, the ability to accurately obtain HRQoL information has become a priority for children living with epilepsy, parents caring for them, and clinicians aiming to direct healthcare toward a patient-centered care model [12,13]. As a result, there is a need for robust, valid, and easily obtainable assessment instruments to use effectively in routine clinical care the overall emotional and social functioning in daily life and life situations. Patient-reported outcome measures (PROMs)

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meet this need because they were developed and validated to collect information on health outcomes. A health outcome is a change in health attributable to a planned intervention or series of interventions and refers to both objective indicators of functional status and subjective indicators of HRQoL. Therefore, by filling out PROMs, patients judge their symptoms, performance, general emotional and social functioning in daily life, their satisfaction with experiences in life situations. On one hand, PROMs completion may prompt patients' self-reflection and help them to identify what is important to them. Additionally, it may give patients to raise some issues with clinicians as it can suggest that they are interested in their views. This implies that the process of PROM completion is not simply a matter of information collection, but it can affect how patients think about their condition and the perception of how clinicians are interested in or take care of them [14]. On the other hand, PROMs raise clinicians' awareness of patients' problems, offering a comprehensive self-report of their symptoms and functioning, ad well as of their personal aims, desires, and hopes. This is expected to prompt clinicians to go into these issues showing patients that they consider not only biomedical information but also the patient experience [15].

When patients cannot report for themselves (e.g., due to limited cognitive or communication abilities), information about their difficulties and concerns about living with a chronic disease is collected from parents or caregivers (the so-called proxy reports). Nonetheless, caregivers are not always optimal reporters of children's experiences (e.g., [16,17]) given the observed disagreement between children and their caregiver reports – the so-called "proxy problem" [18]. Past research showed that it depends on the domain of interest. That is, parents' assessment of their child is likely to correlate closely with the self-report when rating their child's performance on concrete, observable functioning (e.g., motor ability). Still, correlations are expected to be poorer on emotional measures (e.g., anxiety, depression, well-being) and abstract issues about their child's internal life [16,19]. Thus, if the caregiver underestimates or overestimates them, these discrepancies could result in undertreatment or overtreatment of needs, worries, and preferences [17]. Referring to epilepsy, it was shown that parents are not aware of the child's quest for normality; and, in contrast to their parents, children are not concerned about the future [20,21].

While there is a clear distinction between patient reports, which are not interpreted by anyone else, and proxy reports, in which someone answers as if they were the patient [22], there are several reasons why an HRQoL measure in pediatric epilepsy should include both patient-report and proxy-report versions. First, the proxy-report is needed in some cases because patients cannot report for themselves due to limited cognitive or communication abilities. Second, when feasible, the direct patients' report should not be overlooked. Third, the possibility of collecting information from both the child and the caregiver allows one to depict a more detailed picture of the same patient. Therefore, starting from the systematic review by Crudgington et al. [23] on pediatric epilepsy-specific PROMs, we conducted a scoping review aiming at assessing which scale including both parent and caregiver versions, is more suitable for collecting reliable and useful HRQoL information in pediatric patients with epilepsy. We focused on studies that reported their level of agreement as an indicator of the accordance of the two versions in collecting information.

2. Methods

This scoping review is part of the project entitled "Quality of life after pediatric epilepsy surgery in Italy: assessment tools and clinical, socio-economic, and environmental predictors" funded by the LICE (Italian chapter of ILAE) Foundation and is registered in OSF https://doi.org/10.17605/OSF.IO/DCT2Z. The search strategy began with the analysis of the childhood epilepsy questionnaires identified in the most recent systematic review on the topic [23] as having better measurement properties and/or including proxy and parent reports, i.e., the *Quality of Life in Childhood Epilepsy* (QoLCE) [24,25], *Pediatric Quality of Life Inventory – Epilepsy Module* (PedsQL-EM) [26] and *Health-Related Quality of Life Measure for Children with Epilepsy* (CHEQoL) [20]. We included the QoLCE because, despite it is a proxy-report PROM, we aimed to ascertain if it had never been administered also to patients, especially the shorter 16-item form. As a second step, we searched for studies on the development of new epilepsy-specific PROMs (regardless they were patient and/or proxy reports) from 2019 onwards combining terms for HRQoL in pediatric epilepsy with generic terms for PROMs such as questionnaire, measure, tool, and scale. Finally, in this review, we focused on studies that included both child and parent report scales and analyzed the agreement between their ratings. Some of them were mentioned in Crudgington et al. [23] and others were not.

The databases PubMed, Web of Science, PsycINFO Scopus were searched in December 2023. Finally, English-language full report articles published in international peer-reviewed journals that focused on developing epilepsy-specific PROMs or adapting/validating existing ones were included. Articles were excluded if they were focused only on patient-report or parent-report questionnaires and do not evaluate the agreement between child and caregiver ratings.

3. Results

Forty-three papers were initially identified, but 35 of which 24 reviewed by Crudgington et al., [23] were excluded for the following reasons: a) 30 articles included only proxy- or only patient-report scales; 5 included both types of reports but did not assess the agreement between them (Fig. 1).

To provide some details about the 11 papers not reviewed by Crudginton et al. (2019) [23] and not included in the current review for the above-mentioned reasons reasons reported in Table 1:

1) *Scale with proxy- or patient- report*: only one new measure has been developed since 2019, namely the *Pediatric Epilepsy Learning Healthcare Life* (PELHS-QoL-2) [35]. However, PELHS-QoL-2 is a proxy-report measure consisting of two questions to determine the impact of seizures and medication side effects on HRQoL in children aged from 0 to 18 years. Some new linguistic adaptations of the QOLCE-55 (Arabic version [36], Spanish version [37]) and QOLCE-16 (Chinese version [38], Spanish version [39]) were identified. In line with the characteristics of the scales, only the caregiver reports were collected, with one exception.

2) *Scale with proxy- and patient- report but without agreement evaluation*: Sousa et al. [40] administered the Brazilian Portuguese version of the QOLCE-55 to 32 caregivers and 16 children, but they did not compare the two versions or evaluate their agreement. Similarly, new linguistic adaptations of the CHEQOL-25, which include both patient- and proxy-report versions, either referred only to the child version (Czech version [41]) or administered the patient- and proxy-reports in two separate studies (Malay version [42,43]) making it impossible to evaluate their agreement. Baars et al. [44] described the development of the condition-specific modules of the European DISABKIDS including the Epilepsy module. The scale assesses the HRQoL in children and adolescents with epilepsy from proxy and caregiver perspectives, but the level of agreement was not reported. Similarly, Follansbee-Junger et al. [45] described the development of the PedsQL-EM through focus groups and cognitive interviews, but they did not address the issue of agreement.

The contents of the 8 articles selected following the above-mentioned criteria are summarized in Table 1.

One study for each of the following two scales was identified. The *Quality of Life in Pediatric Epilepsy* (QoLPES) [27] was developed following consultation with children and parents who were asked to list in order of importance their concerns, which were then aggregated and transformed into items by researchers. Concerns like medication side effects, cognitive effects of epilepsy, psychosocial effects, and schooling were common to both parents and children. Of the concerns listed by the children, hatred of seizures, dislike of hospital visits, dating, social

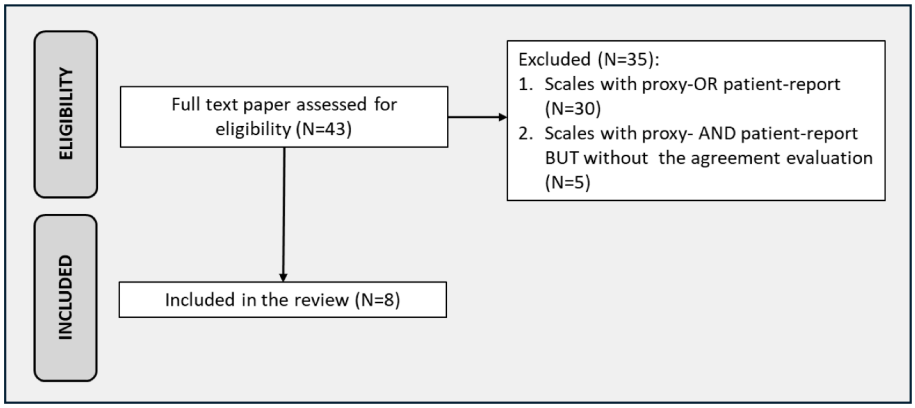

Fig. 1. Flowchart illustrating the selection of eligible studies.

embarrassment, and headaches were not identified by the parents. Parent-child agreement on the *Hague Restrictions in Childhood Epilepsy Scale* (HARCES) [28] was moderate (ICC = 0.36, 95 % CI: 0.03, 0.58) with some disagreements about restrictions in daily activities.

Two studies investigated the psychometric properties and the agreement of the *Pediatric Quality of Life Inventory – Epilepsy Module* (PedsQL-EM) [26,29]. Overall, the scale showed adequate psychometric properties. Modi et al. [26] reported that the intraclass correlations for caregiver-child dyads ranged from 0.45 to 0.60 with the lowest degree of concordance for the sleep and mood/behavior measures, and the better for the executive functions. However, Hulse and colleagues [29] showed significant differences between children and their parents on the PedsQL-EM, with parents reporting poorer overall scores across subdomains.

Five studies referred to the CHEQoL-25 [20], which encompasses both patient-report and proxy-report versions. This questionnaire includes overlapping as well as distinct items to account for the differences observed between caregivers and patients. Verhey et al. [30] reported a general concordance of 0.45 on the CHEQOL-25 with the greatest discrepancies for the Secrecy (0.24) and Present worries (0.32) scales. Other studies concern the CHEQoL-25 linguistic adaptation in Serbian [31], Chinese [32], Vietnamese [33], and Kenyan [34]. The Serbian version [31] showed adequate agreement (0.43–0.57) between the children's and parents' reports. The parent proxy-report and the child self-report of the Chinese version [32] showed a good level of agreement on the Interpersonal/Social [(ICC) = 0.670, $p < 0.001$] and Secrecy (ICC = 0.417, $p = 0.048$) scales, while a lower agreement was observed for the Present worries and Intrapersonal/Emotional scales. For the Vietnamese version [33], ICCs ranged from 0.35 to 0.66, indicating moderate to good agreement between proxy and patient reports. The Interpersonal/Social and Present worries scales had the highest agreement (ICC values were 0.62 and 0.66, respectively), whereas the Intrapersonal/Emotional and Secrecy scales had a highest degree of discrepancy (ICC values were 0.35 and 0.44, respectively). Finally, the Kenyan CHEQoL-25 [34], parent and child questionnaires correlated well for Interpersonal/Social ($p = 0.001$) and Intrapersonal/Emotional ($p = 0.004$) scales, but not for the Present worries and Secrecy.

4. Discussion

The current study reviewed the existing literature on pediatric epilepsy-specific PROMs to identify measures that include both patient-report or parent-report questionnaires. Our focus was on the level of agreement between respondents (i.e., patient and proxy) to assess the usability of both versions in measuring HRQoL in children with epilepsy. In fact, epilepsy-specific measures of HRQoL that include self-report and proxy-report versions are particularly valuable, as they enable physicians to gather information from different sources that may also be complementary to each other. For instance, proxy responses offer insights when patients cannot report for themselves, as the self-reports do when children can express their perceptions concerning the disease. Finally, the combination of self-report and proxy-report responses provides a more comprehensive understanding of the patient's condition.

In line with Crudgington et al. [23], this review confirms that a small number of epilepsy-specific HRQoL PROMs with these characteristics exist. We identified four scales (namely, the QoLPES, the HERCES, the PedsQL-Epilepsy Module, and the CHEQoL-25), which offer self-report and proxy-report versions.

Overall, we confirmed that caregivers are not in complete agreement when reporting children's perceptions about the impact of epilepsy on their lives [18], but we documented a moderate to high agreement between the parent proxy and child self-report. Previous research on general measures of HRQoL or related to other diseases have shown that agreement is better when ratings are on concrete and observable aspects (e.g., [16,17,46]) and poorer for emotional features and internal life (e.g., [16,19]). This aspect was not fully confirmed by our findings. Our review suggests that for epilepsy-specific PROMs there is a good agreement between the parent proxy and child self-report in the interpersonal aspects such as interacting with peers or school-related social difficulties [27,30–34], but also in intrapersonal aspects there are some levels of concordance. Namely, with the exception of the Chinese version of the CHEQoL-25 [32], significant correlations between the proxy and patient reports were observed when referring to negative and positive feelings, worries, needs, and preferences [26,30,31,33,34]. A possible explanation is that, except for Modi et al. [26], these results referred to the patient-report and proxy-report versions of CHEQoL-25 that were developed including many overlapping items, but also distinct items tailored on the differences between caregivers and patients (Ronan et al., 2003) [30]. Another possible reason is that some studies were conducted with young children (Hussain et. al, 2020) [31] and it was provided evidence that discrepancies tend to increase as children grow older [47].

Looking in detail at the specific scales, only a single study investigated the psychometric properties and the patient-proxy agreement of the QoLPES and the HERCES, making an effective evaluation of their strength impossible. Regarding the PedsQL-EM, the scale has adequate psychometric properties [26,29], but Hulce et al. (2020) did not confirm the Modi et al.'s [26] results, as they found significant differences between children's and their parents' reports in different subdomains. Finally, the CHEQoL-25 has extensively documented psychometric properties [23,48] confirmed by the various linguistic adaptations, and an extensive analysis of the agreement between the proxy-report and self-report scales derived from the original and the translated versions.

All these features suggest that the CHEQoL-25 has great potential for assessing HRQoL in children with epilepsy. Even if the use of the CHEQoL-25 is limited to a population of children aged 8 to 17 years who

Table 1
Studies evaluating epilepsy-specific patient reported outcome measures including both patient-report and proxy-report ratings and their level of agreement.

Author and Measure	Aim	Sample	Patients' age	Items and Scales	Concordance between patient and caregiver
Arunkumar et al. [27] Quality of Life in Pediatric Epilepsy (QoLPES)	To develop proxy- and patient- reports on quality-of-life in children with epilepsy.	Forms were completed by *N* = 80 parents and by *N* = 48 children.	3 month −18 years	Items: 20	Contents common to both parents and children: medication side effects, cognitive effects of epilepsy, psychosocial effects, and schooling. Contents not identified by parents: hatred of seizures, dislike of hospital visits, dating, social embarrassment, and headache.
Bedard et al. [28] The Hague Restrictions in Childhood Epilepsy Scale (HARCES)	To determine the parent–child agreement and identify the clinical factors associated with parent–child disagreement.	*N* = 90 children and *N* = 90 mothers	9–17 years	Item: 10	Intraclass Correlation Coefficient (ICC): 0.36
Modi et al. [26] Pediatric Quality of Life Inventory − Epilepsy Module (PedsQL-EM)	To validate an epilepsy-specific measure with parallel child and caregiver reports to assess HRQoL in children with various seizure types, treatments, and demographic characteristics.	*N* = 260 children and *N* = 260 parents	2–18 y	Item: 29 (patient self-report versions) with the toddler and young child versions having fewer items and 26 to 33 (proxy-report versions). Scales: 5 - Impact - Cognitive functioning - Sleep - Executive functioning - Mood/Behavior	Intraclass Correlation Coefficient (ICC): Impact: 0.56 Cognitive functioning: 0.54 Sleep: 0.46 Executive functioning: 0.60 Mood/Behavior: 0.45
Hulse et al. [29] PedsQL-EM	To examine the application and utility of the PedsQL-EM in an ambulatory clinic setting, the agreement of parent and child QOL ratings, and the scale's sensitivity to clinical factors reported to influence QOL in pediatric epilepsy.	*N = 127 children and N = 151 parents*	8–18 y	See above.	Paired sample t-tests (M ± SD), * $p <$ 0.01 Impact: 7.4 ± 19.5* Cognitive Function: 14.3 ± 25.0* Sleep: 8.5 ± 25.0* Executive Functioning: 9.4 ± 26.1* Mood/Behavior: 8.9 ± 22.3*
Verhey et al. [30] Health-Related Quality of Life Measure for Children with Epilepsy (CHEQoL-25)	To examine differences in patient- and proxy- reports and examine their reliability.	*N* = 375 children and *N* = 378 parents	6–15 years	Items: 25 Scales: 5 - Interpersonal/Social - Present worries - Intrapersonal/Emotional - Secrecy - Quest for normality (only patient version) - Future worries (only proxy version)	Intraclass Correlation Coefficient (ICC): Interpersonal/Social: 0.49 Present worries: 0.32 Intrapersonal/Emotional: 0.49 Secrecy: 0.24
Stevanovic et al. [31] CHEQOL-25	To validate the Serbian version of the CHEQoL-25 patient- and proxy-reports.	*N* = 50 children and *N* = 50 parents	8–12 years	See above.	Intraclass Correlation Coefficient (ICC): Interpersonal/Social: 0.43 Present worries: 0.56 Intrapersonal/Emotional: 0.57 Secrecy: 0.52
Wo et al. [32] CHEQOL-25	To validate the Chinese version of the CHEQoL-25 patient- and proxy-reports.	*N* = 50 children and *N* = 50 parents	8–18 years	See above.	Intraclass Correlation Coefficient (ICC): Interpersonal/Social:0.67 Present worries: *ns* Intrapersonal/Emotional: *ns* Secrecy: 0. 24
Tri et al. [33] CHEQOL-25	To validate the Vietnamese version of the CHEQoL-25 patient- and proxy-reports.	*N* = 77 children and *N* = 77 parents	8–18 years	See above.	Intraclass Correlation Coefficient (ICC): Interpersonal/Social: 0.62 Present worries: 0.66 Intrapersonal/Emotional: 0.35 Secrecy: 0.44
Hussain et al. [34] CHEQOL-25	To validate the Kenyan version of the CHEQoL-25 patient- and proxy-reports.	*N* = 177 children and *N* = 177 parents	7–15 years	See above.	*p*-value associated to Kappa statistics: Interpersonal/Social: $p < 0.001$ Present worries: *ns* Intrapersonal/Emotional: $p < 0.004$ Secrecy: *ns*

understand language at a grade 3 reading level [30] and the response format (described below) may be challenging, especially for children with cognitive impairments, it has several strengths. First, as mentioned above, tailored proxy and patient versions of the questionnaire were developed with direct involvement of children with epilepsy and their caregivers [49]. This approach has the potential to increase the understanding of QoL of people with neurological disabilities by capturing both proxy and patient perspectives independently. Secondly, focus group discussions with children with epilepsy revealed their functional limitations but also their hopes and desire for normality. Therefore, the CHQOL-25 is a broader measure of QoL, rather than simply a scale focused on biopsychosocial functioning. Third, items were formulated using paired opposite phrases, the so called *structured alternative format* [50], which helps minimize some potential biases. The effectiveness of this question format is related to the implication that some children perceive themselves in a way, whereas others see themselves in the opposite manner. After the selection of the first choice, the child is asked to decide if the option is "sort of" or "really" *true* for them. This format

improves the understanding of negatively worded sentences, reduces social desirability biases (as it avoids possible response as “false” or “not like me”), and captures variability by providing a broader range of response choices.

This review suggests that it is crucial to collect information on HRQoL in patients with epilepsy from multiple informants. However, several factors can influence the degree of accordance among them. Proxies often fail to recognize the patient’s ability to adapt and adjust their goals and expectations through shifting internal standards and values. For example, the ‘disability paradox’ [10] challenges the reliability and validity of proxies’ responses because the patient’s adaptation to new life circumstances, which often leads to improved QoL, might occur more rapidly than a proxy can capture. Other response biases can be identified in longitudinal studies such as that of Fayed et al. [47] on child-parent dyads in childhood epilepsy. Their findings. reveal: (i) poorer proxy ratings when compared to the child’s self-reports due to parental stress or difficulties in adjusting to the child’s disease; (ii) age-related discrepancies, especially in the concealment of epilepsy, which tend to increase as children grow older; (iii) overly positive proxy ratings when they are unaware of the child’s social difficulties outside the home (e.g., low peer support).

Although discrepancies exist, capturing both child and parent evaluations of child’s QoL provides a deeper understanding of their perceived challenges and concerns [8]. This, in turn, enables better support and counseling to individual children and families. For example, on one hand, some issues (like secrecy experienced by children and youth with epilepsy) may be more accurate if reported directly by the patients. On the other hand, some children may lack cognitive maturity to reflect on their future experiences of living with epilepsy. In such cases, proxies provide valuable insights that might otherwise go unreported.

Finally, the potential limitations of our scoping review were our strict inclusion criteria. We included only full-text and peer-reviewed articles published in English. Therefore, other instruments developed in other languages and not published in international journals might exist that have adequate psychometric quality, include both parent and caregiver versions, and report their level of agreement.

5. Conclusions

This scoping review highlights the need of using PROMs that enable the collection of information from the caregiver and patient in pediatric epilepsy to gather information about the impact of the disease on the children’s lives from multiple perspectives. While further studies are needed to investigate the agreement between patient and caregiver-reports, the CHEQoL-25 appears to be the best candidate for assessing health-related quality of life by combining self-report and proxy-report measures in the clinical setting.

CRediT authorship contribution statement

Francesca Chiesi: Writing – original draft, Conceptualization. **Carlotta Tagliaferro:** Writing – original draft, Methodology, Data curation. **Pietro Cappelletto:** Writing – review & editing. **Carmen Barba:** Writing – review & editing, Funding acquisition, Conceptualization.

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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.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2025.110334.

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