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Investigation of the quality of life of children and adolescents with epilepsy: An integrative review

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Abstract

The main purpose of this integrative review was to investigate the Health Related Quality of Life (HRQOL) of children with epilepsy worldwide. Secondary objectives were to identify the factors that influence HRQOL and the tools used to measure it. A literature search was conducted in the PubMed, Scopus, and Google Scholar electronic databases in English using the combination of keywords ("quality of life") AND [("pediatric epilepsy") OR ("childhood epilepsy")]. The final number of reports included was 21. The main theme of all studies was the examination of HRQOL of children/adolescents with epilepsy. Specifically, 3 articles focused on surgical treatment, 1 on pharmacological treatment, 4 on sleep, 4 on psychological and behavioral factors, 6 studies evaluated, measured, and recorded HRQOL and 3 studies analyzed the effect of the health system and the quality of care provided. In all studies where children with epilepsy were compared to a healthy group, their HRQOL scores were lower.

Keywords: Childhood epilepsy, quality of life, integrative review

Introduction

Many healthcare professionals worldwide have been involved in researching this multidimensional and complex chronic disease, analyzing the various forms of epilepsy, its causes, pharmacological treatment, and alternative therapies. In recent years, there has been a growing recognition of the importance of Health Related Quality of Life (HRQOL) as an important measure for assessing the impact of disease on daily life [1], leading to an increase in primary research, but there are few reviews in the field of HRQOL in children with epilepsy. With this integrative review health scientists will have a comprehensive picture of the HRQOL of these patients and will be able to offer holistic care and better treatment to pediatric patients.

Purpose

The main purpose of the review was to investigate the HRQOL of children with epilepsy worldwide so that this paper could fill the gap in the literature and serve as a basis for future primary research in the same population in Greece. Secondary objectives were: a) to identify the factors that influence QoL in children with epilepsy and b) to identify the tools for measuring HRQOL in these children.

Materials and Methods

A literature search was performed in January 2025 in PubMed, Scopus, and Google Scholar electronic databases in English using the combination of keywords ("quality of life") AND [("pediatric epilepsy") OR ("childhood epilepsy")]. The inclusion criteria were: 1) publication between 1/2021 and 12/2024, 2) the study population had a diagnosis of epilepsy, 3) the age of the population must be up to 18 years. The study included research papers of any methodological design and excluded reviews of any kind, meta-analyses, and case studies.

The main research question asked was "What was the HRQOL of children and adolescents with epilepsy over the last three years?" and an attempt was made to answer this question on a global level. The secondary objectives also raised the questions "What factors influence their HRQOL?" and "What tools are used to measure their HRQOL?" The integrative review

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methodology described by Whittemore & Knafl [2] was followed. The methodological quality of the studies was assessed by two independent researchers and the Prisma method [2020] [3] as shown in detail in the flow chart (Supplementary Figure 1).

Results

A total of 24, 502 records were identified. After using automation tools, 21, 884 records were classified as ineligible. After removing duplicates, the total number of records evaluated was 2, 365. During the review, 2, 319 records were deemed ineligible based on their title and abstract. Therefore, 55 reports were evaluated for eligibility based on their entire text. Of these, 10 reports were excluded from the study due to an unrepresentative sample (small sample, biased sample selection) (reason 1), 6 were rejected because the research focused on factors not directly related to children's HRQOL (reason 2), 9 because the study sample included individuals over the age of 18 (reason 3), 4 were reviews of any type (reason 4), 2 did not take into account important variables (such as seizure frequency) (reason 5), 1 showed bias on the part of the parents (reason 6), while in 2 others the information on the research methodology was incomplete and methodological errors were identified, so they were not included in the study. The final number of reports included in the review was 21. For better analysis and understanding of the results, the survey data are presented in three subgroups: HRQOL assessment by parents/caregivers, HRQOL assessment by children/adolescents, and assessment by both groups. Detailed information on study characteristics, outcome measures, and key results of the included studies is presented in Supplementary Table 1.

Assessment by parents/caregivers

Widjaja, *et al.* [4] studied HRQOL in children with drug-resistant epilepsy (DRE) (aged 4-18) before and after epilepsy surgery (lesion resection surgery) compared to others who were treated with antiseizure medication (ASM). The tool they used to measure HRQOL was the Quality of Life in Childhood Epilepsy scale (QOLCE-55), which was completed by the parents. Their research showed that the HRQOL of children with DRE improved significantly 6 months after surgery and remained so for at least two years. Specifically, the average QOLCE-55 scores for the group with ASM were: first measurement 57.21, 6 months later 59.58, 1 year later 59.76 and 2 years later 62.15, while those of the surgery group were: preoperatively 58.18, 6 months later 63.83, 1 year after 65.91 and 2 years after 67.43. The operated patients had a higher HRQOL of 3.0, 4.9 and 5.1 points at 6 months, 1 year, and 2 years after surgery, respectively, compared to patients on ASM. 72% of the children who underwent surgery were seizure-free compared to 33% of the children with ASM two years later. The parents of those who were seizure-free reported higher HRQOL.

Based on the same sample more research was conducted by Smith, *et al.* [5], who examined the effect of treatment type (surgical or pharmacological) on HRQOL and the factors that may influence their relationship. Specifically, the association with seizure control, symptoms of depression in children or parents, and family resources were investigated. The results showed that 2 years later, children who had undergone surgery had an average HRQOL score of 65.65 and children on ASMs had 60.72, and after adjusting for the basic covariates of the first recording, the difference was 3.4 points. This finding is mainly due to the freedom of patients from seizures, with 66% of the effect of surgery attributed to seizure control, while the effect of seizure control was not influenced by the other factors examined.

The HRQOL of children with seizures after surgical resection to treat them examined Wu, *et al.* [6]. More specifically, they assessed the outcomes of seizures and HRQOL in a sample of 151 children (aged 4-16) using the Children with Epilepsy Quality of Life (CHEQOL-25): Parent and Child Questionnaire 1, 3 and 5 years postoperatively. The outcome of the children's seizures was assessed based on the International League Against Epilepsy (ILAE) classification of seizure outcomes (ILAE) classification of seizure outcomes: 1: Seizure-free, 2: Only benign seizures, 3: Almost seizure-free, 4: Significant improvement, 5: Partial improvement, 6: No improvement or worsening). From the study sample, 28.5% of children had seizures 1 year after surgery. Their average HRQOL at 5-year follow-up was 63.5, with 48.8% having worse HRQOL than before surgery, 58.5% having ILAE 3-4, and 41.5% having ILAE 5-6. Preoperative language delay or language dysfunction and postoperative ILAE classification of seizure outcome were significantly associated with HRQOL. In contrast, preoperative factors (seizure type, seizure frequency, and ASM), factors related to surgery (surgical complications, incomplete resection, and surgical sequelae), household income, and caregiver education level were not statistically associated with HRQOL.

The effect of the number of ASM on HRQOL in a 10-year prospective cohort study examined Nabavi Nouri, *et al.* [7] in a sample of 195 children (aged 4-12) with epilepsy using the QOLCE-55 tool. Specifically, they assessed whether children exposed to more than one ASM, compared to those exposed to none or one in the first 2 years after diagnosis, had poorer HRQOL 10 years later. The results of the study showed that the mean HRQOL scores were 72.4 at baseline, 77.3 at the 2-year follow-up, and 78.72 at the 10-year follow-up. At the 2-year follow-up, the mean HRQOL was lower in children who received a higher number of ASMs, with children with more than one ASM having a HRQOL of 72.6, those with one 78, and those with none 86.4. The number of ASMs at 2 years was significantly associated with HRQOL at 10 years. Therefore, children who received one ASM had better HRQOL compared to those who received more than one and worse HRQOL compared to those who did not receive any ASM. It is important to note that the association between ASM and HRQOL was no longer significant when the child's clinical characteristics, family factors, and HRQOL at the 2-year follow-up were included in the model.

The relationship between sleep and neurodevelopmental characteristics in HRQOL was studied by Winsor, *et al.* [8]. To examine sleep, they used the method of actigraphy with the use of a device (Actiwatch) by the children and the completion of the Children's Sleep Habits Questionnaire (CSHQ) by the parents. HRQOL was assessed using the QOLCE-55 tool by parents. The sample consisted of 36 children with epilepsy and 14 without epilepsy. Of the children with epilepsy, 78.13% scored above the clinical threshold for significant sleep disturbance. In contrast, actigraphy showed no significant differences in sleep between children with and without epilepsy. No significant differences in HRQOL were found between epilepsy types. Sleep problems reported by parents were significant predictors of HRQOL, in contrast to seizure severity and number of ASM, which were not found to be associated in this study. When neurodevelopmental characteristics were considered in the analysis, sleep problems were no longer significant predictors of HRQOL, indicating a possible mediating effect and showing that neurodevelopmental characteristics were a more important factor than sleep problems. The time it takes for a child to fall asleep appeared to be associated with worse HRQOL, especially in children with ADHD. This finding suggests that ADHD may be a fundamental factor in ADHD, with sleep disturbance appearing as a secondary prognostic factor.

In the field of sleep is also included the study by Joseph, *et al.* [9], which investigated the sleep habits and their correlation with HRQOL in 50 children (aged 4-18) with epilepsy in a hospital in eastern India. The children's HRQOL was measured by their parents using the Quality of Life in Childhood Epilepsy scale (QOLCE- 16). The mean total HRQOL score for the children was 50.78. More specifically, on the cognitive functioning subscale, the score was 65.50, on the emotional subscale 54.87, the social subscale 29.87, and the physical subscale 52.87. There was a significant correlation between medication adherence and HRQOL in children with epilepsy, while 15% of the HRQOL score was predicted by medication adherence. The study also revealed that the number of siblings was significantly associated with HRQOL, with children with epilepsy who had one sibling having better QoL (60.82). There was a significant relationship between seizure types and sleep habits, with children with simple focal seizures experiencing more sleep problems. A moderate negative significant correlation was found between HRQOL and sleep habits, meaning that as the HRQOL score of children with epilepsy increased, the sleep problem decreased. Sleep habits also significantly predicted the HRQOL of children with epilepsy, specifically, a one-point increase in the HRQOL score was expected to lead to a decrease in the sleep score by -0.29.

The association between sleep disorders, behavioral problems, and HRQOL investigated Zhao, *et al.* [10] in 167 children (aged 3-12) with epilepsy using the Pediatric Quality of Life Inventory (PedsQL) 4.0 tool. 73% of the sample had sleep disorders with significantly lower HRQOL scores in the areas of emotional, social, and school functioning and psychosocial health. Sleep anxiety, disturbed breathing during sleep, daytime sleepiness, and the total score for sleep disorders were significantly associated with the total HRQOL score. The diagnosis of BECTS was significantly associated with both a higher total score for behavioral problems and a lower total HRQOL score, while taking two or more ASMs was significantly associated only with a lower total HRQOL score.

The mediating effect of sleep quality between HRQOL and factors affecting HRQOL in children with epilepsy was studied by Yan, *et al.* [11] in a sample of 212 children with epilepsy and 79 healthy children aged 4-12 years in China. Sleep problems were negatively associated with children's HRQOL, Similarly, all subscales of the QOLCE-16 questionnaire were negatively correlated with the total score of the tool for sleep conditions, and various sleep indicators were significantly correlated with lower HRQOL. DRE and video EEG abnormalities had a direct effect on the HRQOL of children with epilepsy. Seizure frequency in the last month, DRE, and video EEG abnormalities had an indirect effect on HRQOL through sleep quality.

A study in India [12] investigated the relationship between HRQOL in children with epilepsy, variables related to seizures, and psychopathology. The children's HRQOL was measured based on reports from their parents/guardians using the QOLCE tool and the results showed that HRQOL scores were significantly higher for children with mild/moderate seizure severity scores, with an IQ in the normal range (p=0.015), while lower scores were reported for psychopathological problems. Finally, the psychopathology score and IQ explained 43% of the variance in the total HRQOL score of children with epilepsy.

Using the same scale for measuring HRQOL (QOLCE) Schraegle & Titus [13] conducted their research on a sample of 82 children (aged 6-18) with temporal lobe epilepsy. The aim was to explore the possible pathways through which executive function and depressive symptoms affect the QOLCE of these children. The results showed that both executive dysfunction and depressive characteristics were negatively associated with the children's HRQOL. Furthermore, depressive characteristics were associated with lower executive function, ASM, and the presence of hippocampal sclerosis. Reduced executive function was associated with parental psychiatric history and family stress. In addition, there was an indirect relationship between executive function and HRQOL through depressive characteristics. Executive function mediated the relationship between reduced HRQOL and positive parental psychiatric history as well as increased family stress. The relationship between reduced HRQOL and a higher number of ASMs was fully mediated by depressive characteristics. The indirect relationship between depressive characteristics and the parents' positive psychiatric history was mediated by executive function. Similarly, it was found that executive function fully mediated the relationship between increased family stress and depressive characteristics in young people. In contrast, the mother's level of education and ASM were not significant predictors of executive function, nor were there any significant correlations between sociodemographic factors and executive function.

In the study by Abdollahi, *et al.* [14], the mothers of 206 children with epilepsy and 211 healthy children (aged 4-18) were asked about their children's HRQOL (QOLCE) in order to assess and compare it, as well as to highlight the impact of epilepsy on their lives. The mean total QOLCE score for the group of children with epilepsy was 74.3, lower than that of the control group, which was 87.9. More specifically, the subscales of the QOLCE tool had lower scores among children with epilepsy compared to the control group, apart from the scores for language and anxiety, which were not statistically significant. The authors did not investigate the existence of a correlation between HRQOL and possible factors, but they did highlight the following observations: children who had not had a seizure during the previous year had higher HRQOL scores than those who had, while HRQOL was higher among children who had not been hospitalized for seizures than among those who had been hospitalized. Finally, children with epilepsy who had adverse effects from ASM had lower HRQOL scores compared to those who did not.

Using the same tool (QOLCE-55 1st edition), the impact of epilepsy on children aged 10-18 years in a city in India was assessed in the study by Pachange, *et al.* [15]. According to the results of the study, the prevalence of epilepsy was found to be 3.20 per 1000 children. The overall mean HRQOL score was 69.9. Of the subgroups of the measurement tool, physical functioning was the most impaired, with the lowest mean HRQOL score of 58.3, while the highest score was in social functioning with 81.4. The current age of the child, the age at the first episode, and the time since the last seizure were statistically significantly related to HRQOL. In contrast, parental education, socioeconomic status, and seizure type were not found to be associated with HRQOL. The treatment gap (cost of treatment, unavailability of medication, low literacy rates, lack of information) was found to be 70.4%.

On a sample of only 33 children (aged 4-14) using the QOLCE-55 questionnaire Winsor *et al.* [16] conducted their study to assess the frequency of anxiety, depression, and sleep problems in parents of children with epilepsy and to determine the impact of these variables and other comorbidities in children on their HRQOL. The results show that symptoms of parental anxiety, depression symptoms, and sleep problems were all significant predictors of children's HRQOL. However, when children's coexisting sleep problems and neurodevelopmental characteristics were included, parental variables were no longer significant.

The aim of the study by Gao, *et al.* [17], conducted in China on a sample of 136 children (aged 4-14) with various types of epilepsy, using parental reports and the PedsQL questionnaire, was to evaluate the effect of a hospital-community-family ternary linkage continuous nursing model (hospital-community-family ternary linkage continuous nursing model) on compliance, cognitive functioning, resilience, and HRQOL in children with epilepsy. Consequently, the children were divided into two groups: the observation group and the control group. The first group followed the new model and the second group followed the routine care model. The new model encouraged collaboration between agencies, provided continuous support, better communication, and education, and tailored the care plan to the individual needs of the child and family. During the 6-month follow-up, the observation group had significantly higher scores in compliance, resilience, and HRQOL compared to the control group. The total HRQOL scores for the observation group were 80.24 and for the control group 75.88. More specifically, the scores for physical functioning, emotional health, and behavioral functioning were higher compared to those before treatment. The total HRQOL score was correlated with seizure frequency, per capita family income, and grouping.

A similar study conducted Zhuang, *et al.* [18] in China. In a sample of 127 children with epilepsy (aged 3-12 years), they investigated the effect of continuous nursing care based on the Omaha system on the psychological state, self-esteem, and HRQOL of children with epilepsy. The children were divided into two groups (observation and control) and after discharge, the children in the control group received regular guidance outside the hospital, while the children in the observation group received continuous nursing intervention based on the Omaha system, in addition to the usual guidance outside the hospital received by the children in the control group. The psychological state, self-esteem, sense of defect, and HRQOL of the two groups were compared before and three months after the intervention. HRQOL was measured using Professor Mark Sabaz's Quality of Life Scale for Children with Epilepsy (sub-scales: emotional and physical status, behavioral problems, cognitive and social functioning). The scores of each HRQOL subscale in the two groups after the intervention increased significantly compared to the levels before the intervention, and the HRQOL scores in the observation group were significantly higher than those in the control group after the intervention on all subscales.

Another original study was conducted in Iran by Nemati, *et al.* [19], which evaluated the effect of a family empowerment program on the HRQOL of children with epilepsy. The researchers randomly divided a sample of 80 children with epilepsy into two groups: the experimental group and the control group. The first group received educational sessions for parents on the nature of epilepsy and the care of their children, while the second group received no intervention. The children's HRQOL was measured using the QOLCE tool by parents before the intervention and one month after. The results showed that the mean HRQOL score in all subgroups increased in the experimental group compared to the control group.

Assessment by children/adolescents

In the research by Saleh, *et al.* [20] was studied the HRQOL of children and adolescents (9-16 years old) with epilepsy in Egypt, compared to a control group, using only self-reporting with the World Health Organization Quality of Life - BREF tool (WHOQOL-BREF). The total QOL score for the patient group was 35.75 and for the control group 57.44. Similarly, in all subgroups, the HRQOL scores of children with epilepsy were lower, with physical health having the lowest (42.92) and social life having the highest (48.18). There was also a statistically significant negative correlation between age and psychological domain scores, between the number of school failures and psychological and environmental domains, as well as the duration of the disease and the duration of treatment with all areas of quality of life. In contrast, a statistically significant positive correlation was found between the social class score and the general and environmental domains. Finally, a correlation was also found between the type of seizures and a statistically significant reduction in the general and environmental domains among children who had generalized, and focal seizures compared to those who had absence seizures.

Using the Pediatrics Quality of Life Inventory version 4.0 (PedsQL 4.0 SF 15), Aronu, *et al.* [21] conducted their research in the city of Enugu, Nigeria. Specifically, they compared the HRQOL of a group of 166 children and adolescents with epilepsy aged 5-18 years with a control group of healthy children. The results showed that there were significant differences in the mean HRQOL scores between children with epilepsy and the control group in the areas of school functioning (57.7 vs. 80), psychosocial integration (69.7 and 78.1), and psychosocial and physical activities (74.9 and 80.5). School functioning scores below 50 were significantly higher in children with epilepsy (32.5%) compared to healthy children (6.6%). Similarly, low HRQOL scores in the psychosocial combination and in psychosocial and physical activities were significantly higher in the group of children with epilepsy (12.7% and

7.2%, respectively) compared to the control group (6.6% and 3%, respectively). Low scores in the emotional domain were significantly more common in individuals aged 8-12 and 13-18 (20% and 18.8%, respectively). HRQOL scores below 50 in the school functioning domain were significantly more common in individuals aged 5-7 years (44.8%), while in the 8-12 age group they were 28.3% and in the 13-18 age group they were 22.9%. The HRQOL for school functioning was statistically different between the two genders. Significantly, more girls (43.1%) compared to boys (25.7%) had HRQOL scores below 50 in school functioning. The mean HRQOL scores for children with epilepsy in social functioning for the upper and lower grades were 84.68 and 155.57, respectively. Children from the upper social class scored higher in the social functioning domain, and social class was significantly correlated with scores in the social domain.

Assessment by both groups

In their study, Brothers, *et al.* [22] examined the cumulative impact of three factors on the HRQOL of children and adolescents (aged 5-18) with epilepsy using the Pediatric Quality of Life Inventory (PedsQL) Epilepsy Module with parallel completion by children and parents/caregivers. Specifically, along with HRQOL, they examined the adverse effects of ASM, accompanying mental health and behavioral disorders, and sociodemographic characteristics. The study involved 281 young people with epilepsy and their caregivers. Caregivers' reports of their children's HRQOL showed that externalizing problems, behavioral problems, and adaptive skills explained 58% of the variance in HRQOL on the cognitive functioning subscale of young people, while the children's self-reports showed that externalizing problems, behavioral problems, and adaptive skills explained only 36% of the variance in HRQOL in the cognitive functioning subscale. Similar results were observed for the executive functioning subscale, where caregivers' reports on HRQOL showed that internalization problems, behavioral problems, and adaptive skills explained 65% of the variance in executive function, while in self-reports by young people, internalizing problems and behavioral problems explained 34% of the variance in HRQOL in executive functioning.

Overall, the results showed that the strongest common predictors of HRQOL, both for young people and parents/caregivers, were mental and behavioral health problems. In detail, other common predictors were adverse effects from ASM and polypharmacy, which affected the sleep and impact subscales, respectively. Another interesting finding was that in both groups, fewer externalization problems predicted worse HRQOL (cognitive function) and fewer internalization problems predicted lower HRQOL levels (executive function). Only from the children's self-reports was it found that younger patients reported a greater disease burden in daily life and more difficulties in cognitive function, while female gender was associated with worse HRQOL on the mood/behavior subscale. From the parents/caregivers' perspective, the strongest predictors in most domains were mental health and behavioral variables, followed by epilepsy-specific predictors (adverse effects of ASM, duration and control of epilepsy, polytherapy). Finally, in contrast to the group of children, male gender was associated with worse HRQOL in the cognitive and executive function subgroup.

Alnaamani, *et al.* [23] measured HRQOL in a sample of 101 children aged 5-18 years with epilepsy in a hospital in Oman in the Middle East using the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales questionnaire. The data from their study showed that the effect of epilepsy on children's HRQOL was inversely proportional to their age. Based on the reports of both groups, HRQOL in the younger age group (5-7 years) was more affected by epilepsy, and HRQOL in the older group (13-18 years) was less affected. There was no significant difference between the sexes, except for significantly higher HRQOL scores reported by parents for adolescent girls. Overall, the HRQOL score reported by parents (78.3) was lower than the HRQOL score of children (80.3).

Among all domains, school functioning had the lowest HRQOL score, while social functioning had the highest score for both children and parents. Among the four domains, the lowest HRQOL score reported by parents (55.4) was observed for school functioning in the 5-7 age group. The maximum gender-related difference in the HRQOL scores reported by parents was observed for emotional functioning, with a statistically significant difference (boys = 79.6, girls = 68.5). Also, based on parental reports, polytherapy with ASM was associated with lower total HRQOL scores. Seizure-free duration and total HRQOL scores were positively correlated. Children with a seizure-free period of ≥ 3 years had better HRQOL scores (89.43) than those with a seizure-free period of 1-2 and < 1 year ($p=0.009$). Higher seizure frequency had a negative effect on the HRQOL reported by parents and was the most important clinical factor affecting it. The parent-reported HRQOL score was affected by age of onset in all four domains, suggesting that the earlier the onset of epilepsy, the greater the negative impact on HRQOL. Children from nuclear families had better HRQOL scores than those from single-parent families (79 vs. 51), while HRQOL was lowest in children whose seizures began before the age of 3.

A study conducted in Turkey [24] compared the HRQOL, the levels of anxiety and depression of children with epilepsy and their families with those of healthy children, while also investigating the value of children's self-reporting in assessing their HRQOL. The tools used to measure the children's HRQOL were the KINDL General QoL Scale (for the control group) and the KINDL-Epilepsy Module (for the epilepsy group), which were completed by the children themselves and their parents. The results showed that the HRQOL scores of the group of children with epilepsy (67.06) were statistically lower than those of the control group (74.04), particularly in the areas of emotional well-being, family, and friends. Parents of children with epilepsy reported lower emotional well-being for their children compared to parents of healthy children. Children with epilepsy and other comorbidities had lower scores on all KINDL subscales and significantly lower HRQOL compared to children with epilepsy without comorbidities. There was a negative correlation between HRQOL (KINDL Epilepsy) and depression, child anxiety, and parental anxiety, while there was a positive correlation between KINDL Epilepsy and all KINDL subscales (parents) and parental HRQOL.

Discussion

The concept of HRQOL is often used in the health sector, but it is perceived differently by each patient and health professional. There are many tools for measuring HRQOL, each with its own subscales, but conceptually they all have the same dimensions. From the results of Alnaamani, *et al.* [23], Pachange *et al.* [15], who measured HRQOL in children with epilepsy, it was found that the subgroups with the lowest scores were physical, school, and emotional functioning. It is noteworthy that social functioning was found to be low in the study by Joseph, *et al.* [9], while the highest scores were recorded in the studies by Alnaamani, *et al.* [23] and Pachange, *et al.* [15]. In studies comparing patient and control groups, all subgroups of the HRQOL tools completed either by children with epilepsy or their parents had lower scores compared to the control groups. Specifically, the subscales of the HRQOL that had the lowest scores were family [24], physical [14, 20], and school functioning [21], while social functioning again had the highest score [14, 20].

The unpredictable nature of seizures and concern for their child's future may lead parents to be overprotective of their child's daily activities and restrict them, which explains the low scores on the physical functioning subscale. Similarly, children or adolescents themselves may experience anxiety about seizures and/or the side effects of the ASM they are taking, limiting themselves. The low scores on the school functioning subscale are justified by the negative correlation between the number of school failures found by Saleh, *et al.* [20], while they may also be due to frequent absences from school due to seizures, which negatively affect the child's performance. In all studies comparing children with epilepsy to a healthy group, their HRQOL scores are lower, an expected finding that is confirmed by many studies [25].

Factors that appear to have a positive correlation and influence the HRQOL of children with epilepsy are freedom from seizures [5], the time since the last seizure, age at first onset [15, 23], medication adherence, number of siblings [9], parental HRQOL [24], nuclear family [23], and socioeconomic class [20, 21]. In contrast, factors that appear to have a negative correlation and affect the QoL of children with epilepsy are the duration of the disease and treatment [20, 22], type of epilepsy [11, 20], ADHD [8], seizure frequency [23], sleep problems [10, 11], diagnosis of BECTS epilepsy [10], number of ASM [10, 23], executive dysfunction, depressive characteristics [13, 24], mental and behavioral health problems, anxiety in children and parents [24], ASM side effects, and polypharmacy [22]. It is important to note that in the study by Nabavi Nouri, *et al.* [7], the association between ASM and HRQOL was no longer significant when the child's clinical characteristics, family factors, and HRQOL at the 2-year follow-up were included in the model.

Previous studies [26, 27] confirm the findings of Alnaamani, *et al.* [23] and Brothers, *et al.* [22] that associate younger age with worse HRQOL. This may be because younger children may have insufficient disease management skills to process their condition and have more restrictions on activities, either due to their own anxiety or that of their parents. In contrast, older children are generally more independent, more aware of their capabilities, and in some cases can make decisions about their health and activities and take on some of their own care. While the above provides a good explanation for the data, Pachange, *et al.* [15] and Saleh, *et al.* [20] found that older children have worse HRQoL, with Aggarwal, *et al.* [28], Arya, *et al.* [29], Nadkarni, *et al.* [30], and Shakya, *et al.* [31] agreeing. his may be because as children grow older and enter adolescence, they generally perceive more negative aspects of life and develop a more negative attitude towards epilepsy. Furthermore, it is very likely that adolescents have had epilepsy from an early age, with a longer duration of illness and treatment, thus suffering more years of seizures, the effects of possible polypharmacy, and the overall burden of their illness, making their HRQOL worse because of these factors.

From the research of Smith, *et al.* [5], Widjaja, *et al.* [4], and Wu, *et al.* [6], it appears that freedom and release from seizures, which can be achieved after epilepsy surgery, plays an important role in HRQOL, but the main goal of surgery is to improve the child's HRQOL and not just to control seizures.

Research by Gao, *et al.* [17], Zhuang, *et al.* [18], and Nemati, *et al.* [19] shows that HRQOL depends on the type and quality of care that children and their families receive. More specifically, when care continues after discharge from the hospital, children and parents learn about epilepsy and its treatment repeatedly, and healthcare professionals are available to them, HRQOL is better. Providing regular and ongoing education to patients and families should be part of the core activities of healthcare staff.

The results of Abdollahi, *et al.* [14] on the factors of freedom and release from crises and adverse effects from ASM also suggest a correlation, thus supporting the above findings. Factors that may have a positive influence are mild/moderate severity of crises, intelligence quotient within the normal range, and low scores for psychopathological problems [12]. On the contrary, factors that appear to have a negative effect are comorbidity [24], but the data require further research [32].

Neurodevelopmental characteristics have a mediating effect or secondary role in children's HRQOL, as they are negatively associated with sleep, thus affecting HRQOL [8]. Executive function mediates the relationship between reduced HRQOL and parents' positive psychiatric history and increased family stress. The relationship between reduced HRQOL and a higher number of ASM is fully mediated by depressive characteristics [13]. The research by Joseph, *et al.* [9] correlates the type of epilepsy with sleep habits and, consequently, HRQOL, but it contradicts previous studies that showed the opposite (33-35).

In most studies, there was no significant difference in HRQOL between the sexes. An exception was the results of Alnaamani, *et al.* [23], with significantly higher HRQOL scores reported by parents for adolescentgirls, and Aronu, *et al.* [21], where most girls had low HRQOL scores in the area of school functioning and Brothers, *et al.* [22] where female gender was associated with worse HRQOL on the mood/behavior subscale behavior subscale based on children's self-reports, and male gender was associated with worse HRQOL in the cognitive and executive functioning subscale based on parents' reports. Sociocultural differences may explain the above findings.

Also interesting are the findings of Winsor, *et al.* [16], who found that parents' sleep problems and symptoms of parental anxiety and depression are predictive of children's HRQOL, but removing them from the equation when they include children's sleep problems and neurodevelopmental characteristics. The contribution of parental variables to children's ADHD has an indirect effect resulting from the influence of children's variables on parental variables. These findings have important clinical utility, as they provide evidence for the role of coexisting conditions in children's

HRQOL, which are often overlooked during care.

Similarly, Schraegle & Titus [13] show that while parental psychiatric history and increased family stress negatively affect HRQOL, the relationship is mediated by executive function. This suggests that, in the context of an adverse family environment, children's executive functions may be more vulnerable and pose unique risks for reduced SWB. The findings also suggest that depressive characteristics fully mediate the relationship between current ASM and youth HRQOL. Therefore, regular psychological assessment of parents would be an important addition to the overall treatment of pediatric epilepsy.

Assessment by parents/caregivers

The main drawback of the studies by Abdollahi, *et al.* [14], Gao, *et al.* [17], Joseph, *et al.* [9], Malhi, *et al.* [12], Nabavi Nouri, *et al.* [7], Nemati, *et al.* [19], Pachange, *et al.* [15], Schraegle & Titus [13], Smith, *et al.* [5], Widjaja, *et al.* [4], Winsor, *et al.* [8, 16], Wu, *et al.* [6], Yan, *et al.* [11], Zhao, *et al.* [10], Zhuang, *et al.* [18] is that they derived results regarding the HRQOL of children and adolescents with epilepsy solely through reports from parents. This can lead to bias, overestimation or underestimation of the actual conditions and, consequently, inaccuracy in the results.

Of the 16 studies, 1 collected information only from mothers' reports [14], and 5 other studies had a majority of mothers [4, 5, 7, 16, 19], and the remaining 10 studies did not report a specific number, but in some cases the tools were also completed by caregivers. Mothers are usually the primary caregivers, know more about their children's health, accompany them to medical appointments, and have at least a basic education, so they were chosen by the researchers to complete the HRQOL tools for their children. In addition, in many cases, one of the parents may take a break from work to focus on caring for a child with a chronic illness [36]. This is usually the mother, depending on the country, religious and cultural beliefs, and the family's financial situation.

In the study by Wu, *et al.* [6], HRQOL decreased as the classification of seizure outcome ILAE increased and was an independent prognostic factor. Increased seizures have negative effects on children's neurodevelopment and cognitive function, while also hindering children's participation in social activities, completion of their school education, and avoidance of the stigma associated with epilepsy. At the same time, uncontrolled epilepsy is usually accompanied by more ASM and lower cognitive function due to ASM. In this way, a higher seizure classification leads to a reduction in the HRQOL score.

Finally, the studies by Smith, *et al.* [5], Widjaja, *et al.* [4], and Wu, *et al.* [6] involved patients after surgery for epilepsy. Parents/guardians and patients may have received psychological support in the context of surgery, in which case this factor may not have been apparent.

Assessment by children/adolescents

There were two studies that assessed HRQOL based solely on reports from children/adolescents [20, 21]. The small number may be due to the fact that children may not have been able to complete the tools either because of their age or because of low mental maturity or low cognitive ability. While self-reporting is theoretically the best method of data collection in the case of pediatric patients, there may be underestimation or overestimation of a condition, with age playing an important role in this.

Assessment by both groups

Studies that examined the HRQOL of children with reports from both the children themselves and their parents/caregivers were conducted by Alnaamani, *et al.* [23], Brothers, *et al.* [22], and Ünalp, *et al.* [24]. This method of data collection eliminates a large degree of bias and makes it easy to distinguish differences and similarities in their reports. Alnaamani, *et al.* [23] found a general trend of lower scores according to parents' reports as opposed to children's scores, while Ünalp, *et al.* [24] found the opposite.

Previous research has yielded mixed results regarding parent-child agreement, while some studies have shown that there is good agreement for some, but not all, areas of HRQOL and that children's reports may be less reliable than those of parents [37]. This observed discrepancy may be due to the fact that a child may be well adjusted to daily life with epilepsy, unlike parents who may be concerned about their child's social, cognitive, and emotional challenges by comparing them to children of the same age.

Conclusion

The HRQOL of children and adolescents with epilepsy is generally low, with many factors playing an important role in this. In order to improve it, factors related to epilepsy and affecting its treatment, psychological, family and socioeconomic factors, sleep, psychological factors of parents/guardians, the care plan followed by the healthcare team, and the healthcare system in general. Therefore, holistic care is required, rather than just treating the disease or reducing seizures, as was previously believed.

Limitations

The volume of information presented in this integration review was quite large, and for this reason, the team limited itself to investigating the QoL of children with epilepsy highlighting the factors that influence QoL, and only presenting the tools used to measure it, without analyzing or evaluating these tools. Even more conclusions could have been drawn, but this is a separate study and has been done in the past [38]. Finally, the review included studies published only during the three-year period 2021- 2024 and published in English.

Conflict of interest statement

The authors declare that they have no conflict of interest. This publication is the result of a thesis by the author TKE, written as part of her postgraduate studies at the National and Kapodistrian University of Athens, Department of Medicine, in the program "General and Specialized Pediatrics: Clinical Practice and Research". This review was not funded by any organization.

References

1. Ronen GM, Streiner DL, Rosenbaum P. Health-related quality of life in childhood epilepsy: Moving beyond seizure control with minimal adverse effects. Health Qual Life Outcomes. 2003;1(1):36.
2. Whittemore R, Knafl K. The integrative review: Updated methodology. J Adv Nurs. 2005;52(5):546-553.
3. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, *et al.* The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. BMJ. 2021;372:n71.

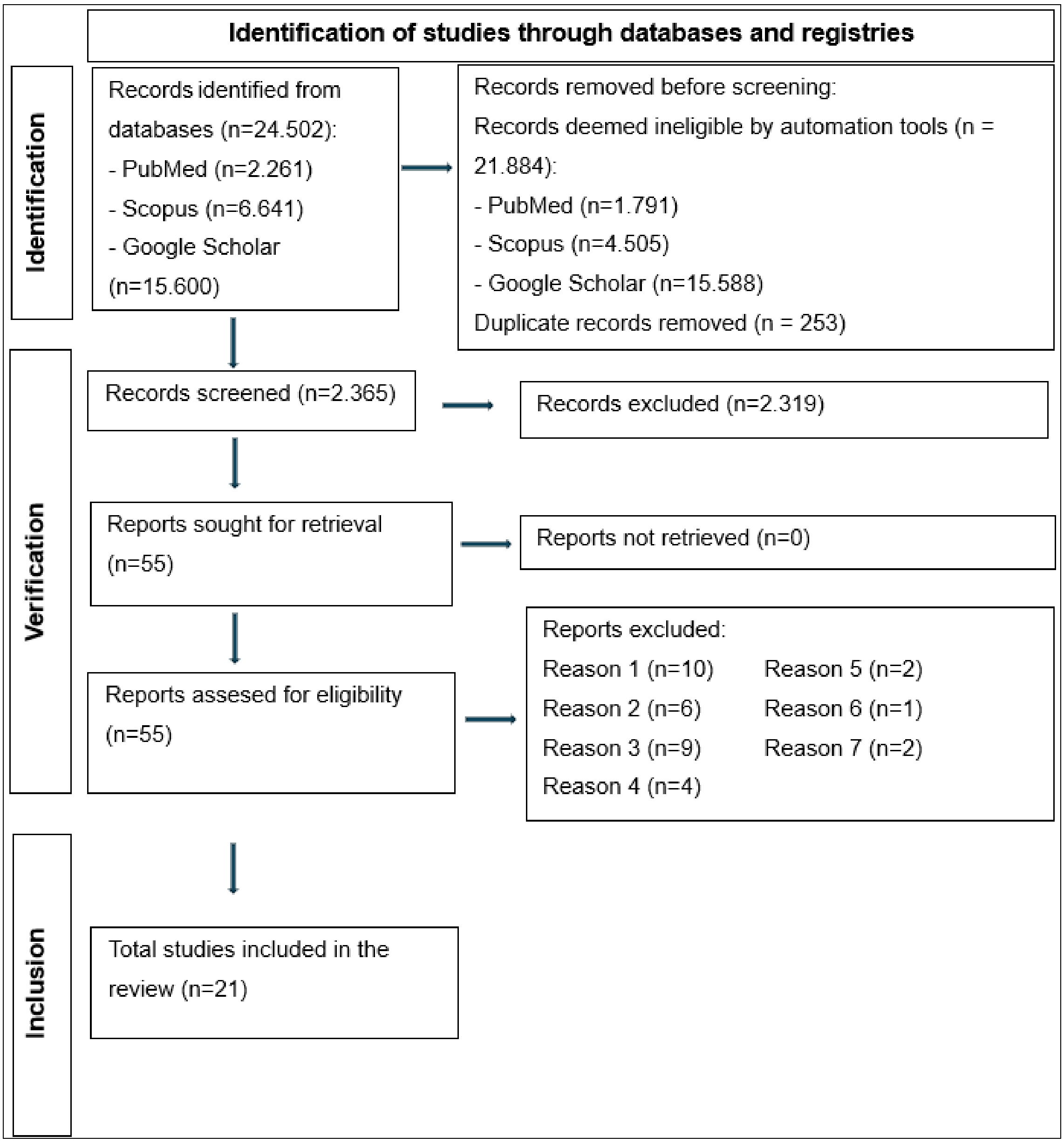
4. Widjaja E, Puka K, Speechley KN, Ferro MA, Connolly MB, Major P, *et al*. Trajectory of health-related quality of life after pediatric epilepsy surgery. JAMA Netw Open. 2023;6(3):e231095.
5. Smith ML, Puka K, Speechley KN, Ferro MA, Connolly MB, Major P, *et al*. A longitudinal cohort study of mediators of health-related quality of life after pediatric epilepsy surgery or medical treatment. Epilepsia. 2023;64(8):2162-2171.
6. Wu Y, Zhang Z, Liang P, Zou B, Wang D, Zhai X. Quality of life of children with residual seizures after epileptic resection surgery. Front Neurol. 2022;13:905317.
7. Nabavi Nouri M, Puka K, Palmar K, Speechley KN. Impact of number of antiseizure medications on long-term health-related quality of life in children with epilepsy: A prospective cohort study. Seizure. 2022;99:120-126.
8. Winsor AA, Richards C, Seri S, Liew A, Bagshaw AP. Contribution of sleep and co-occurring neurodevelopmental conditions to quality of life in children with epilepsy. Epilepsy Res. 2023;194:107279.
9. Joseph H, Digal M, Benny A, Singh D, Vijayan L, Kaur S, *et al*. Quality of life and its relation with sleep habits of children with epilepsy from Eastern India. J Educ Health Promot. 2023;12(1):200.
10. Zhao F, Sun X, Wang Y, Zhou Y, He Y, Wang C, *et al*. Sleep disturbances in Chinese children with epilepsy: Associations with behavioral problems and quality of life. Nat Sci Sleep. 2022;14:1225-1236.
11. Yan L, Chen J, Xie L, Li T, Hu Y, Hong S, *et al*. Mediating effects of sleep quality between clinical characteristics and quality of life in children with epilepsy: A cross-sectional study from Southwest China. Epilepsy Behav. 2024;154:109738.
12. Malhi P, Annam A, Singhi P. Psychopathology and quality of life in children with epilepsy: A cross-sectional study. Indian J Pediatr. 2021;88(7):712-714.
13. Schraegle WA, Titus JB. Executive function and depressed mood are independently disruptive to health-related quality of life in pediatric temporal lobe epilepsy. Epilepsy Behav. 2021;115:107654.
14. Abdollahi M, Abbasi-Kangevari M, Kolahi AA, Farsar AR. Comparison of health-related quality of life among children with epilepsy and a healthy control group in Tehran. J Pediatr Neurol. 2021;19(3):166-172.
15. Pachange PN, Dixit JV, Choudhary AM, Goel AD. Quality of life among middle and secondary school children with epilepsy. J Neurosci Rural Pract. 2021;12(3):490-494.
16. Winsor AA, Richards C, Seri S, Liew A, Bagshaw AP. Quality of life in children with epilepsy: The role of parental mental health and sleep disruption. Epilepsy Behav. 2024;158:109941.
17. Gao Y, Tang X, Wen Y, Qian D, Pan X, Zhang L. Effects of a hospital-community-family continuous nursing model on quality of life in children with epilepsy. Transl Pediatr. 2022;11(2):239-248.
18. Zhuang C, Wu H, Lin B, An X. Effect of Omaha system-based continuous nursing care on psychological status and quality of life in children with epilepsy. Am J Transl Res. 2021;13(4):3435-3442.
19. Nemati H, Mahdavi Khanouki Z, Ghasempour M, Amirifar AA, Alaeikarahroudi F, Gholami M. Effect of family empowerment model on quality of life in children with epilepsy: A randomized controlled trial. Iran J Child Neurol. 2021;15(4):55-65.
20. Saleh SHA, Mohammed MEH, Abounaji OA. Health-related quality of life in Egyptian children and adolescents with epilepsy. Egypt J Hosp Med. 2021;85(2):3772-3777.
21. Aronu AE, Uwaezuoke N, Chinawa JM, Bisi-Onyemaechi A, Ojinnaka NC. Health-related quality of life in children and adolescents with epilepsy in Enugu. Niger J Clin Pract. 2021;24(4):517-524.
22. Brothers SL, Clifford LM, Guilfoyle SM, Wagner JL, Junger K, Huszti H, *et al*. Key predictors of epilepsy-specific health-related quality of life in youth with epilepsy. Epilepsy Behav. 2023;149:109381.
23. Alnaamani A, Ahmad F, Al-Saadoon M, Rizvi SGA, Al-Futaisi A. Assessment of quality of life in children with epilepsy in Oman. J Patient Rep Outcomes. 2023;7(1):65.
24. Ünalp A, Kutlu A, Karaoğlu P, Yılmaz Ü, Çakaloz B. Evaluation of quality of life and psychiatric aspects of children with epilepsy and their families. Turk Arch Pediatr. 2022;57(3):282-289.
25. Stevanovic D, Tadic I, Novakovic T. Health-related quality of life in children and adolescents with epilepsy: A systematic review. In: Epilepsy in children: Clinical and social aspects. Rijeka: InTech; 2011.
26. Berg AT, Langfitt JT, Testa FM, Levy SR, DiMario F, Westerveld M, *et al*. Global cognitive function in children with epilepsy: A community-based study. Epilepsia. 2008;49(4):608-614.
27. Chung K, Liu Y, Ivey SL, Huang D, Chung C, Guo W, *et al*. Quality of life in epilepsy: Insights from people with epilepsy and support groups. Epilepsy Behav. 2012;24(2):256-263.
28. Aggarwal A, Datta V, Thakur LC. Quality of life in children with epilepsy. Indian Pediatr. 2011;48(11):893-896.
29. Arya V, Gehlawat V, Kaushik J, Gathwala G. Parent-reported quality of life in children with epilepsy from Northern India. J Pediatr Neurosci. 2014;9(1):17-21.
30. Nadkarni J, Jain A, Dwivedi R. Quality of life in children with epilepsy. Ann Indian Acad Neurol. 2011;14(4):279-282.
31. Shakya S, Shakya R, Poudel P, Shrestha AK. Quality of life assessment in pediatric epilepsy. Int J Epilepsy. 2020;6(2):54-58.
32. Baca CB, Vickrey BG, Caplan R, Vassar SD, Berg AT. Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. Pediatrics. 2011;128(6):e1532-e1543.
33. Ekinci O, Okuyaz Ç, Gunes S, Ekinci N, Kalınlı M, Tan ME, *et al*. Sleep problems in pediatric epilepsy and ADHD: Impact of comorbidity. Epilepsy Behav. 2017;71:7-12.
34. Oyegbile-Chidi T, Harvey D, Eisner J, Dunn D, Jones J, Byars A, *et al*. Relationship between sleep, cognition, and behavior in children with newly diagnosed epilepsy. Front Neurol. 2022;13:913489.
35. Winsor AA, Richards C, Bissell S, Seri S, Liew A, Bagshaw AP. Sleep disruption in children and adolescents with epilepsy: A systematic review and meta-analysis. Sleep Med Rev. 2021;57:101416.
36. Hatzmann J, Peek N, Heymans H, Maurice-Stam H,

Grootenhuis M. Consequences of caring for a child with a chronic disease. J Child Health Care. 2014;18(4):346-357.

37. Ferro MA, Avery L, Fayed N, Streiner DL, Cunningham CE, Boyle MH, *et al*. Child- and parent-reported quality of life trajectories in children with epilepsy. Epilepsia. 2017;58(7):1277-1286.

38. Lemmon ME, Huffstetler HE, Reeve BB. Measuring health-related quality of life in pediatric neurology. J Child Neurol. 2020;35(10):681-689.

Supplementary



Supplementary Figure 1: PRISMA 2020 flow chart

Reason 1= Unrepresentative study sample (small sample, biased sample selection, inactive epilepsy)
Reason 2= Emphasis on factors not directly related to QoL
Reason 3= Sample included individuals over 18 years of age
Reason 4= Reviews of any type
Reason 5= Important variables were not taken into account (seizure frequency, ASM side effects)
Reason 6 = Parent bias
Reason 7 = Incomplete information on research methodology and methodological errors

Supplementary Table 1

Authors - Date	**Sample - Type of epilepsy - Country**	**Purpose**	**Method - Tool (parents/children)** [1]	**Results**	**Conclusions**
Yan, *et al.* - 2024	212 children with epilepsy and 79 healthy children aged 4-12 – Various types of epilepsy - China	To investigate the association between Quality of Life (QoL), sleep quality, and factors affecting QoL in children with epilepsy.	Cross sectional study - QOLCE-16 (parents)	Various sleep indicators were significantly associated with lower QoL. Differences were observed depending on the type of epilepsy, frequency, and resistance to treatment.	Sleep quality is a mediating factor in the relationship between clinical characteristics and QoL. Improving sleep could improve QoL.
Winsor, *et al.* - 2024	33 children with epilepsy aged 4-14 years - Various types of epilepsy - United Kingdom	To assess the prevalence of anxiety, depression, and sleep problems among parents of children with epilepsy and to determine the impact that these and other childhood conditions have on their QoL	Cross sectional study - QOLCE-55 (parents)	Parental anxiety, depression, and sleep symptoms were predictors of children's QoL. When children's sleep problems and neurodevelopmental characteristics were included, parental variables were no longer significant predictors of QoL.	Coexisting disorders in children mediate the relationship between parental variables and children's QoL. Support for these could improve the QoL of children and their parents
Widjaja, *et al.* - 2023	265 children aged 4-18 - DRE - Canada	Assessment of QoL in children with DRE after surgery compared to ASM.	Prospective cohort study - QOLCE-55 (parents)	Children who underwent surgery reported improved QoL.	The high cost of surgical treatment is justified and access to it should be made easier.
Winsor, *et al.* - 2023	36 children with epilepsy and 14 without, aged 4-16 – Various types of epilepsy – United Kingdom	Investigation of the relationship between sleep, neurodevelopme ntal characteristics, and QoL	Cross sectional study - QOLCE-55 (parents)	78.13% had sleep problems that affected QoL regardless of seizure severity and number of ASM. The effect of sleep on QoL is likely mediated by neurodevelopmental characteristics.	Epilepsy management should be multidisciplinary and provide holistic care.
Smith, *et al.* - 2023	265 children aged 4-18 years - DRE - Canada	Investigation of factors affecting QoL after epilepsy surgery.	Longitudinal cohort study - QOLCE-55 (parents)	QoL scores of children who underwent surgery were 3.4 points higher than those for the ASM group at 2 years, with 66% of seizure control attributed to surgery.	Freedom from seizures appears to have a more significant effect on QoL than psychological factors and family resources. This contrasts with other studies.
Brothers, *et al.* - 2023	281 children aged 5-18 - Various types of epilepsy - USA	Investigation of factors affecting QoL based on reports from children and parents.	Cross sectional study - PedsQL Epilepsy Module (parents and children)	The strongest predictors of QoL were mental and behavioral problems according to both reports.	Early identification of mental and behavioral disorders is important for providing an optimal care plan and better QoL.
Alnaamani, *et al* - 2023	101 children aged 5-18 - Various types of epilepsy - Oman	Assessment of QoL in children with epilepsy at Sultan Qaboos University Hospital in Oman.	Cross sectional study - PedsQL 4.0 (parents and children)	Both groups reported lower QoL at younger ages (5-7 years) and higher at older ages (13-18 years). Parents reported lower QoL.	QoL should be an important indicator for the care of children with epilepsy, beyond the simple management of seizures.
Josegh, *et al.* - 2023	50 children aged 4-18 - Various types of epilepsy - Eastern India	Assessment of QoL and sleep habits in children with epilepsy, as well as the connection between them.	Cross sectional study - QOLCE-16 (parents)	Significant correlation was observed between QoL and sleep habits, suggesting that sleep disorders negatively affected QoL.	Educating parents about proper ASM administration and sleep improvement improves QoL in children with epilepsy.
Nabavi Nouri, *et al.* - 2022	195 children aged 4-12 - Various types of epilepsy - Canada	To determine whether children with epilepsy who are exposed to a greater number of ASM during the first 2 years after diagnosis have worse	Prospective cohort study - QOLCE-55 (parents)	The number of ASM in the 2-year period was associated with QoL in the 10-year period. This association was not significant when adjusting for other variables. QoL in the 2-year period was the only variable associated with better QoL scores	Early QoL is a good indicator of long-term QoL and should be taken into account in future studies examining the association between ASM and long-term QoL.

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[1] There are tools for assessing children's QoL that are completed either by the children themselves or by their parents/caregivers. It is specified which group completes the questionnaire. Only tools that measure QoL are mentioned.

		QoL 10 years after diagnosis.		in the 10-year period.	
Wu, *et al.* - 2022	151 children <18 years - Various types of epilepsy - China	To examine the QoL of children experiencing seizures 1 year after surgery and to identify factors affecting their QoL.	Prospective cohort study - CHEQOL-25 (parents)	28.5% of children had seizures 1 year after surgery, and the mean QOL score for children with seizures was 63.5.	For children with seizures after surgery, a lower ILAE grade is acceptable, as it predicts higher QoL.
Gao, *et al.* - 2022	136 children aged 4-14 - Various types of epilepsy - China	To investigate the effect of the "hospitalcommunity family linkage continuous nursing model" on the care of children with epilepsy and how this affects compliance and QoL.	Cohort study - PedsQL (parents)	At the 6-month follow-up, the observation group had significantly higher scores in compliance, resilience, and QoL compared to the control group.	The application of the model can improve the QoL of children with epilepsy and contribute to its better management in the long term.
Zhao F., *et al.* - 2022	167 children aged 3-12 - Various types of epilepsy - China	To investigate the association between sleep disorders, behavioral problems, and QoL in children with epilepsy.	Cross sectional study - PedsQL (parents)	73.7% of children had sleep disorders and lower QoL in areas such as emotional, social, and school functioning.	A holistic approach is needed in the assessment and management of sleep disorders.
Unalp, *et al.* - 2022	60 children with epilepsy and 51 healthy children aged 7-17 - Various types of epilepsy - Turkey	To compare the QoL, anxiety, and depression levels of children with epilepsy and their families with those of healthy children.	Case-control study - KINDL General QoL Scale, KINDLEpilepsy Module (parents and children)	Children with epilepsy had lower QoL and higher levels of anxiety and depression. Comorbidities worsened the results. Children's self-reports provided a better picture of their QoL.	Epilepsy and psychiatric comorbidities negatively affect the QoL of children and parents. The use of self-reported tools is important, and assessment should be holistic.
Malhi, Annam και Singhi, - 2021	79 children aged 6-15 - Various types of epilepsy - India	To examine the relationship between psychopathology, seizure-related factors, and QoL in children with epilepsy.	Cross sectional study - QOLCE (parents)	General health was the most affected area in QoL. Higher levels of psychopathology and lower IQ were associated with worse QoL.	The approach should be multidisciplinary, with an emphasis on psychological support and symptom management to improve QoL.
Panchange, *et al.* - 2021	108 children aged 10-18 - Various types of epilepsy - India	To estimate the prevalence of epilepsy among schoolchildren and assess their QoL.	Cross sectional study - QOLCE-55 (parents)	The incidence was 3.2 per 1000 children. Physical functioning was the most affected dimension of QoL. The student's age, age at onset, and time since last seizure were significantly associated with QoL.	Assessing QoL helps to understand and improve the care and support of these children
Nemati, *et al.* - 2021	80 children aged 4-8 - Various types of epilepsy - Iran	To evaluate the effect of a family empowerment model on the quality of life of children with epilepsy.	Randomized controlled clinical trial - QOLCE (parents)	The group that received the intervention showed significant improvement in all dimensions of QoL compared to the control group.	The application of the model can significantly improve children's QoL, and the active involvement of families in their care is important.
Saleh, Mohammed και Abounaji - 2021	55 children with epilepsy and 55 healthy children aged 9-16 - Various types of epilepsy - Egypt	To investigate the QoL of children and adolescents in Egypt.	Case-control study - WHOQOL-BREF (children)	Children with epilepsy had lower scores in all areas of QoL compared to the control group. QOL was negatively correlated with age at onset, duration of disease, and seizure frequency, while there was a positive correlation with social class.	Emphasis should be placed on interventions that improve psychosocial status and QoL. The management of epilepsy should also include support for mental and social well-being.
Abdollahi, *et al.* - 2021	206 children with epilepsy and 211 healthy children aged 4-18 - Various types of epilepsy - Iran	To determine the QoL of children with epilepsy and compare it with a healthy group of children in Tehran.	Cross sectional study - QOLCE (mothers)	The group of children with epilepsy had a lower mean overall QoL (74.3 vs. 87.9) than the healthy group, and all seven QoL parameters were lower.	Epilepsy significantly affects the QoL of children and their families. Therefore, holistic care and public awareness are essential for better management of the disease.
Aronu, *et al.*	166 children with	To assess QoL in	Cross sectional study	Children with epilepsy had lower	Beyond seizure control,

- 2021	epilepsy and 166 healthy children aged 5-18 - Various types of epilepsy - Nigeria	children with epilepsy and compare it with that of healthy children in the city of Enugu, Nigeria.	- PedsQL 4.0 SF 15 (children)	QoL scores on the subscales: social functioning, psychosocial combination, and psychosocial and physical activity.	epilepsy management should aim to optimize QoL. Care for children should include regular assessment of their QoL.
Zhuang, *et al.* - 2021	127 children with epilepsy aged 3-12 years - Various types of epilepsy - China	To investigate the effect of continuous nursing care based on the Omaha system on psychological status, self-esteem, and QoL.	Cohort study - Quality of life Scale for Children with Epilepsy (parents)	QOL scores in the observation group were significantly higher than QoL scores in the control group.	Continuous nursing care based on the Omaha system is worth promoting and implementing clinically.
Schraegle και Titus - 2021	82 children with epilepsy aged 6-18 years - Temporal lobe epilepsy - USA	To investigate possible pathways through which executive function and depressive symptoms affect QoL.	Cross sectional study - QOLCE (parents)	Executive dysfunction and depressive characteristics are negatively associated with QoL. Family stress and parental psychiatric history affected executive function and therefore the QoL of children.	The integration of psychological support into epilepsy management is recommended.

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