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Research Paper

Quality of life in children with epilepsy: The role of parental mental health and sleep disruption

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ABSTRACT

Background: Parents of children with epilepsy (CWE) are at increased risk of mental health difficulties including anxiety and depression, as well as sleep difficulties. From both the child's and parent's perspectives, health-related quality of life has been shown to be strongly related to parental mental health. However, there is no literature on parental sleep as a predictor of child health-related quality of life. The role of parental variables has been assessed in relation to epilepsy-specific variables (e.g., seizure severity, anti-seizure medications) and how these relate to health-related quality of life, but prior studies have failed to consider the role of co-occurring conditions which are prevalent in CWE. The current study aims to assess how common anxiety symptoms, depression symptoms and sleep problems are in parents of CWE; and to determine the impact these parental variables as well as child co-occurring conditions have on health-related quality of life in CWE.
Methods: 33 CWE aged 4–14 years old were recruited from two hospitals and parents were asked to complete a series of questionnaires assessing both child and parental variables.
Results: It was found that 33.3 % and 12.0 % of parents of CWE experienced clinically significant anxiety and depression symptoms respectively. In addition 67.9 % of parents presented with significant sleep problems. In initial analysis, parental anxiety symptoms, depression symptoms and sleep problems were all significantly predictive of child health-related quality of life. However when co-occurring child sleep problems and neuro-developmental characteristics were included, parental variables were no longer significantly predictive of child health-related quality of life.
Conclusion: These results suggest that child co-occurrences mediate the relationship between parental variables and child health-related quality of life. The current data highlight the need for a systemic approach to epilepsy management and suggest that support for co-occurrences could benefit health-related quality of life for children and their parents.

Abbreviations: **ADHD**, Attention deficit hyperactivity disorder; **ASD**, Autism spectrum disorder; **ASM**, Antiseizure medication; **CSHQ**, Children's sleep habits questionnaire; **CWE**, Children with epilepsy; **CWOE**, Children without epilepsy; **HADS**, Hospital Anxiety and depression scale; **HASS**, Hague seizure severity scale; **ID**, Intellectual disability; **ILAE**, International league against epilepsy; **KMO**, Kaiser-Meyer Olkin; **PCA**, Principal component analysis; **PSQI**, Pittsburgh sleep quality index; **QOLCE**, Quality of life in childhood epilepsy; **SCQ**, Social communication questionnaire; **SD**, Standard deviation; **SELECTS**, Self-Limited Epilepsy with Centrotemporal Spikes.

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1. Introduction

Paediatric epilepsy is associated with a range of co-occurrences including sleep disturbances, behavioural difficulties, and neuro-developmental characteristics. Previous literature has shown these to impact children's health-related quality of life beyond epilepsy specific variables such as seizure severity or anti-seizure medications [1–3]. These co-occurrences not only impact the child but extend to impact families [4,5]. Raising children with epilepsy (CWE) can be difficult for parents, as epilepsy can introduce daily uncertainties which require adjustments for the whole family [6]. The occurrence of even a single seizure can introduce significant disruptions to parents including increased stress, anxiety, depression, and sleep disturbances [7–12]. However, despite the likely bidirectional effects, there has been little examination of how parental variables impact child health-related quality of life, and even less investigation of the relative contribution of parental variables compared to child variables in predicting child health-related quality of life [13]. Understanding the contribution of these two domains can help to optimise epilepsy management and determine what areas need to be prioritised when aiming to improve health-related quality of life in CWE.

Previous literature suggests that between 50 % and 58 % of parents of CWE experience symptoms of depression and anxiety respectively [14,15]. The psychological impact of epilepsy on families is considerable compared to other chronic conditions, with the unpredictability of seizures leaving parents in constant worry [16,17]. Co-occurring factors such as behavioural difficulties have also been found to contribute to parental well-being [8,18,19]. For example, previous research has found [20] that anxiety symptoms were significantly higher in parents of CWE with co-occurring learning and behavioural disabilities, compared to parents of CWE with no co-occurrences.

A limited amount of research has considered the contribution of parental mental health to child health-related quality of life. parental worries about epilepsy have been shown to be related to a decline in child health-related quality of life [2] similarly, others have shown that parental anxiety and depression are negatively related to children's health-related quality of life [19,21,22]. However, across these studies the eligibility criteria were largely permissive, limiting their external validity, whereby children with intellectual disability (ID) were included which would likely amplify the relationship between parental wellbeing and child health-related quality of life [23].

Another important contributor to child well-being is parental sleep. Disturbed sleep patterns have been documented in 38 % to 62 % of parents of CWE [10,24] and can arise because of various factors. These disturbances may result from the child's sleep disturbances, which affect up to 78 % of CWE and can extend to negatively impact parental sleep quality [10,12]. Similarly, parental worries about nocturnal seizures can lead to co-sleeping [11,25,26]. Poor sleep quality in parents of CWE has also been shown to be associated with more severe parental mental health symptoms [11,25], which ultimately contributes to poor child health-related quality of life as outlined above. Despite this, no studies have investigated the direct relationship between parental sleep and child health-related quality of life.

Given the impact of parental variables and child variables [1] to health-related quality of life, understanding their respective contribution can help to prioritise treatment needs. Broader research has assessed the contribution of parental coping versus epilepsy severity to child health-related quality of life and has shown that parental coping was a stronger predictor in determining health-related quality of life than epilepsy-specific variables [27]. Similarly, others [22] have found that parental anxiety was more strongly predictive of child health-related quality of life compared to epilepsy-specific variables. These findings are consistent with previous research, which emphasised that epilepsy goes beyond epilepsy-specific variables [28,29] and that family variables can further complicate management of the disease [30]. However, these studies failed to include co-occurrences, limiting the interpretation of the impact on health-related quality of life.

Contrastingly, one study [31] evaluated the contribution of parents and child psychological symptoms, as well as epilepsy-specific variables to health-related quality of life. surprisingly, they found that parental variables did not significantly contribute to child health-related quality of life. However, they did show that both epilepsy-specific factors (e.g number of antiseizure medications (ASMs), age of onset) and psychological co-occurrences (e.g., mental health symptoms, hyperactivity and inattention) emerged as significant predictors of child health-related quality of life. Interestingly co-occurrences exerted the strongest contribution (over 50 % of variance) compared to epilepsy specific variables which contributed 2.4 %. This study underscores the need to assess the relative importance of parental variables in combination with child co-occurrences when predicting child health-related quality of life. It suggests that the inclusion of co-occurring conditions may alter the perceived impact of parental variables on child health-related quality of life refuting prior research. Thus future research should empirically evaluate and compare the contribution of parental factors vs child co-occurrences to gain a comprehensive understanding of their influence on child health-related quality of life.

In summary, poor mental health and sleep problems are common in parents of CWE. However, when estimating the impact on health-related quality of life, previous research is limited as it has mainly considered the contribution of epilepsy-related variables to parental variables, which fails to allow for the impact of co-occurring conditions. To comprehensively assess health-related quality of life in CWE, it is important to understand the commonality of mental health symptoms and sleep difficulties in parents. Once these are established, evaluating the extent of the contribution of parental variables to child health-related quality of life in addition to co-occurrences will provide a more comprehensive and clinically valuable model of health-related quality of life in CWE.

- Study Aims

1. To investigate the rate and association of sleep disturbances, anxiety, and depression symptoms in parents of CWE
2. To explore the relative contribution to child health-related quality of life of parental mental health and sleep compared to co-occurring conditions in CWE.

2. Material and methods

2.1. Participants

2.1.1. Children with epilepsy

This study was cross-sectional, whereby participants were recruited via two routes: prospective and retrospective. In the primary prospective route, children were recruited from the outpatient clinics within the Neurophysiology departments of The Birmingham Children's Hospital and Worcestershire Royal Hospital from September 2019 to May 2021. Additionally, a retrospective route was employed to recruit children with Self-Limited Epilepsy with Centrotemporal Spikes (SELECTs) as a specific epilepsy type of interest, in addition to the broader groups of focal and generalised epilepsy. SELECTs allows the impact of epilepsy more broadly to be dissociated from the impact of seizures more specifically on both sleep and HRQOL. This route was used once to gather additional participants, with families identified from the hospital database and mailed study materials.

The inclusion criteria for the CWE were: (1) Age between 4 and 16 years; (2) Confirmed diagnosis of epilepsy; (3) Absence of co-occurring intellectual disability (ID); (4) Parents with a sufficient level of spoken English to ensure that the study instructions and questionnaires could be understood. Further clinical information was retrieved from participants' medical records. An epilepsy diagnosis was determined by a neurophysiologist and confirmed by a neurologist according to International League Against Epilepsy (ILAE) 2017 classification. Epilepsy

type was based on electroencephalogram (EEG) presentation. The study was approved by the North West – Preston Research Ethics Committee (REC reference 19/NW/0337). It is acknowledged that the cohort utilised in this study also participated in the study conducted by [1].

2.1.2. Parents of children with epilepsy

Parents of children with epilepsy within the study were also recruited to take part. Once consented, parents were provided with a series of questionnaires to complete for their children and themselves.

2.2. Measures

Child Variables

Child sleep habits were assessed using the Child Sleep Habits Questionnaire [CSHQ, [32] to evaluate sleep patterns over the past week. Subscales within the CSHQ were aggregated to generate a total sleep disturbance score ranging from 33 to 99, with a threshold of > 41 indicating significant sleep disturbance. Neurodevelopmental characteristics were evaluated using the Social Communication Questionnaire [SCQ], [33] to screen for autistic traits. A total score of 15 distinguished between the presence or absence of characteristics, while a higher threshold of 22 provided stronger evidence for an autism diagnosis. The Conners 3 ADHD index [Conners 3AI], [34] was employed to screen for ADHD characteristics, with a T score of 65 indicating scores within the range typically associated with an ADHD diagnosis. Health-related quality of life was assessed using the Quality of Life in Childhood Epilepsy Scale [QOLCE-55], [35], where higher scores indicated better health-related quality of life. Seizure severity was measured using the Hague Seizure Severity Scale [HSSS], [36]), with higher scores indicative of greater seizure severity. These measures were also utilised in the study by [1].

Parental Variables

2.2.1. Parental mental health

Hospital Anxiety and Depression Scale (HADS)

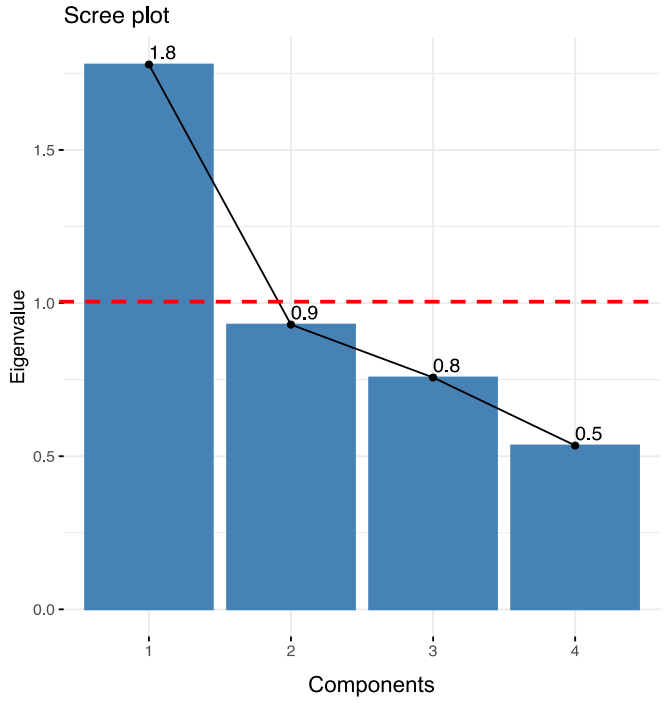

Fig. 1. Scree plot indicating the eigenvalues of each principle component as identified within the PCA. The red dotted line represents Kaiser's (1960) criterion. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

Parental mental health was measured using the HADS [37]. This is a self-report measure which consists of two subscales for anxiety (HADS-A) and depression (HADS-D). Questions are scored on a scale ranging from 0 to 3 to produce a total score between 1 and 21. A score between 0 and 7 corresponds to "normal" symptoms, a score between 8 and 10 suggest the scores fall in the "borderline' range and scores of 11 and over correspond to clinically significant range [38]. The psychometric properties of the HADS including the reliability and correlation between variables are recognised as good [39].

2.2.2. Parental sleep

Pittsburgh Sleep Quality Index (PSQI)

Parental sleep was measured using the PSQI [40] which is widely used clinically. The self-report measure assesses sleep disturbance across seven components including subjective sleep quality, sleep onset latency, sleep duration, sleep efficiency, sleep disturbance, use of sleep medication and daytime sleepiness. The sum of the seven components produces a global PSQI score ranging from 0 to 21, where a cut off score of 5 or more indicates poor sleep quality. The validity and reliability of the measure are recognised as adequate [40].

3. Statistical analysis

All data were initially assessed for normality via use of the Shapiro-Wilks test. In the case where data were not normally distributed ($p < 0.05$), a non-parametric test was used.

Descriptive statistics were used to report demographic variables for CWE and their parents, as well as the scores on the PSQI and HADS. Prevalence rates were reported for the percentage of parents scoring above the clinical cut off on these questionnaires (≥ 5 and ≥ 11) respectively. Correlation analyses were also conducted to assess the relationship between parental sleep quality to depression (Spearman rho) and anxiety (Pearson coefficient) symptoms. Continuous data were presented as mean and standard deviation (SD) and categorical data in the form of frequencies (%). All statistical analyses were carried out using R [41].

3.1. Principal component analysis

Prior to conducting regression analyses, the number of child variables (see Measures section) was reduced using a Principal Component Analysis (PCA), due to the small sample size within the study. PCA with varimax rotation was conducted using the "stats" and "psych" packages in R. To determine the suitability of data for the PCA, the Kaiser Meyer Olkin [KMO], [42] test of sampling adequacy and Bartlett's test of sphericity [43] were used.

The KMO test assesses data suitability for PCA by measuring the strength of the correlation between variables, indicating the proportion of variance that is attributable to an underlying construct, yielding a value between 0 and 1. A figure closer to 1 indicates higher variable correlation and better suitability for analysis. Values below 0.5 are deemed unsuitable. In this study, the KMO yielded a figure of 0.62, indicating data suitability for PCA.

The Bartletts test of sphericity was used to assess whether the intercorrelation between variables, a p value of < 0.05 suggests that there is a sufficient correlation between variables. The Bartlett's test of sphericity was significant $\chi^2(6) = 12.75$, $p = 0.04$, indicating that a PCA was appropriate.

Kaiser's criterion [44] was employed to ascertain the number of components to retain in the analyses. This test suggests retaining components with eigenvalues ≥ 1. In our study, one component was retained as it had an eigenvalue of 1.8 (refer to Fig. 1). This component was defined by three variables (**autistic characteristics, ADHD characteristics and sleep problems**) which loaded strongly and accounted for 45 % of the variance (see Table 1). Subsequently this component was used in the hierarchical linear regression analyses as a summary index

Table 1
Loadings of Principle Component Analysis using four child variables.

Child composite scores	Component			
	1	2	3	4
Sleep disturbances	**0.57**	−0.33	−0.47	0.56
Seizure severity	−0.06	**0.88**	−0.43	−0.14
ADHD characteristics	**0.53**	0.33	0.74	−0.75
Autistic characteristics	**−0.63**	−0.10	0.23	0.32
Proportion of variance explained	44.47 %	23.24 %	18.92 %	13.37 %
Cumulative Variance Explained	44.47 %	67.72 %	86.63 %	100.00 %

Note N = 30, values in bold indicate strongest loading, Rotation Method: Varimax.
1 component extracted.

for the child co-occurring variables.

3.2. Regression analyses

Three regression analyses were performed using R [41] to assess the contribution of parental variables to the relationship between child co-occurring conditions and child health-related quality of life. A total of three models were used with the following predictor variables in each (1) parental sleep quality (2) parental depression symptoms and (3) parental anxiety symptoms respectively. In each analysis, age was inputted in the first step, followed by the respective parental predictor variables in the second step and child co-occurring variables as the third step. The purpose of this approach was to understand how parental sleep quality, depression, and anxiety individually contribute to child health-related quality of life in the presence of co-occurring conditions.

Prior to the regression analyses described above a series of simple linear regression analyses were also conducted to test for the mediator effect [45]. This process included four key steps: First testing the impact of parental variables on predicting HRQOL. Secondly testing the impact of parental variables predicting the mediator variable (child co-occurrences). Thirdly, testing the impact of the mediator variable (child co-occurrences) predicting HRQOL. Finally, testing the impact of both child co-occurrences and parental variables in predicting child HRQOL. If all regression analyses were significant, the mediation criteria was confirmed (See supplementary materials). Bonferroni correction was used to correct for multiple comparisons, where the p-value of 0.05 was divided by the number of comparisons within the family of tests.

4. Results

4.1. Demographic data

4.1.1. Children with epilepsy

An initial sample of 228 participants were approached to take part in the study. From this sample, 70 participants agreed to take part. 17 children were excluded as they did not receive an epilepsy diagnosis, ten due to the presence of an ID, and ten who did not complete the measures to be included in the analysis. The final sample consisted of 33 CWE (M = 9.72 years, SD 2.50 years, range = 4–14 years). Fifteen had a focal epilepsy type (4 x temporal lobe epilepsy, 3 occipital lobe epilepsy, 1 x parietal occipital lobe, 1 x frontal lobe epilepsy, 1 x genetic focal epilepsy, 2 x structural with right hemispheric origin, 3 x no further detail), while 10 had generalised epilepsy (1 x Jeavons syndrome, 9 x no further detail) and 8 SELECTS (Self-Limited Epilepsy with Centrotemporal Spikes). Mean epilepsy duration was 2.03 years.[1] Sample characteristics are presented in Table 2.

[1] Epilepsy duration reported by 29 participants.

4.1.2. Parents of children with epilepsy

Demographic information was reported for 29 parents[2] in total. This sample consisted of 25 mothers (M = 39.64 years, SD = 5.98 years, range = 26–49 years, three mothers' ages missing) and four fathers (M = 48.25 years, SD = 4.43 years, range = 44–53 years).

4.2. Descriptive statistics for parental variables

To assess aim one, parental anxiety, depression and sleep quality scores were calculated, along with the proportion of parents who scored above the cut off scores (see Table 3). The mean parental scores for depressive and anxiety symptoms were 4.64 ± 4.16 and 8.24 ± 4.08 respectively. In terms of prevalence rates, 33.33 % of parents had a score greater than the clinical cut off of 11 on the anxiety scale, while 12.12 % of parents had a score of ≥ 11 on the depression scale. The mean total PSQI score was 7.46 ± 3.98, with 67.86 % of parents scoring above the global cut off (>5) for clinically disturbed sleep quality.

4.3. Relationship between parental sleep quality and mental health symptoms

Correlational analyses were conducted to examine the association between parental sleep quality to anxiety, and depression symptoms. The analyses revealed a significant positive correlation between parental sleep quality and anxiety symptoms ($r(28) = 0.51$, $p = 0.01$). A trend was also revealed for the association between parental sleep quality and depression symptoms (*rho* (28) = 0.38, $p = 0.05$).

4.4. Contribution of parental sleep quality to child co-occurring variables in determining child health-related quality of life

To address the second aim, hierarchical linear regressions were used to compare the contribution of parental and child co-occurring variables (i.e., component one from the PCA) to overall child health-related quality of life. Age of child was entered into the first step; parental variables were inputted in the second step and the child variables were inputted in the final step within all the regression models. The parental variables across the three regression models were sleep quality (Fig. 2), anxiety symptoms (Fig. 3) and depression symptoms (Fig. 4). All data met the assumptions of collinearity and independent errors.

As indicated in Fig. 2, when parental sleep quality was inputted, it was found to be a significant predictor of child health-related quality of life [β = -0.45, t(27) = -2.55, p = 0.02] and contributed to an improvement in the fit of the model, with the variance accounted for increasing by 20.0 % [F(2,25) = 3.74, p = 0.04]. Interestingly, once child co-occurrences were inputted in the third step, there was a significant improvement in the explained variance by 21.2 % [F(3,24) = 6.36, $p = 0.003$]. Simultaneously, the regression coefficient for the association between parental sleep quality and child health-related quality of life was reduced to be non-significant [β = -0.09, t(27) = -0.49, p = 0.63].

4.5. Contribution of parental depression symptoms to child co-occurring variables in determining child health-related quality of life

In model 2 (see Fig. 3), when parental depression symptoms were inputted in step 2, they were found to be a significant predictor of child health-related quality of life [$\beta = -0.50$, t(30) = -3.01, $p = 0.01$] and led to an improvement in the variance accounted for by 23.9 % [F (2,28) = 5.01, p = 0.01]. Once component one (co-occurrences) were added in step 3, they were found to significantly improve the fit of the model,

[2] There was a smaller sample of parents compared to that of the children, as some parents did not complete the questionnaires for themselves although they did complete the measures for their child.

Table 2
Sample characteristics of CWE (N = 33). Values are shown as mean (SD).

	Focal (N = 15)	Generalised (N = 10)	SELECTS (N = 8)	F/χ^2	*DF*	*p* value*	Effect size	Post Hoc Analyses
Demographics				0.13	2	0.88[a]	0.008	
Age, Years (SD)	9.33(2.37)	9.40(3.57)	9.75(1.28)					
Sex				1.72	2	0.92[b]		
Male	12	4	6					
Female	5	6	3					
Number of ASMs				3.09	2	0.21[b]		
0	2	1	6					
1	6	7	3					
2	7	2	0					
Type of ASM								
Levetiracetam	2	5						
Carbamazepine	4	1	1					
Lamotrigine	2	3	1					
Topiramate	2							
Sodium valproate	1	2						
Clobazam	2							
Ethosuximide	1							

p values were derived from one-way ANOVA[a] or Kruskal Wallis test[b].
* $p < 0.05$, Adjusted $p = 0.02$ applied. Differences which remained significant following Bonferroni correction are denoted in bold.

Table 3
Scores on parental questionnaires. Values are shown as mean (SD) and %.

	Mean +/- SD	No of parents above cut off (%)
HADS-A	8.24 (4.04)	33.33 %
HADS-D	4.64 (4.16)	12.12 %
PSQI total score	7.46 (3.98)	67.86 %
PSQI: Sleep quality	1.43 (0.74)	
PSQI: Sleep latency	1.68 (1.09)	
PSQI: Sleep duration	0.89 (0.88)	
PSQI: Sleep efficiency	1.11 (1.23)	
PSQI: Sleep disturbance	1.25 (0.59)	
PSQI: Use of sleep medication	0.11 (0.57)	
PSQI: Daytime dysfunction	1.00 (0.61)	

increasing the variance explained by 19.5 % F (3,27) = 7.63, $p < 0.001$]. This also resulted in the regression coefficient of the association between parental depression symptoms and child health-related quality of life being reduced to a non-significant value [β = -0.20, t(30) = -1.17, p = 0.25].

4.6. Contribution of parental anxiety symptoms compared to child variables in determining child health-related quality of life

In model 3 (see Fig. 4), when parental anxiety symptoms were inputted in step 2, they were found to be a significantly predictor of child health-related quality of life [β = -0.38, t(30) = -2.19, p = 0.04]. They also led to an increase in the variance of the model by 14.30 % [F (1,28) = 4.81, p = 0.04]. Following this, component one (co-occurrences) were inputted in the final step of the model, leading to a significant improvement in model, increasing the variance by 27.0 % [F (3,27) = 7.01, p = 0.001]. The regression coefficient of the association between parental anxiety symptoms and child health-related quality of life was reduced and became non-significant [β = -0.09, t(30) = -0.56, p = 0.58].

5. Discussion

The purpose of the current study was (1) to examine the commonality and relationship between poor sleep quality and mental health symptoms in parents of CWE; and (2) to explore the relative contribution of parental variables compared to child variables in predicting overall child health-related quality of life. With respect to the first aim, the data revealed that for anxiety and depression symptoms, 33.3 % and 12.1 % of parents scored above the clinical thresholds. In addition, 68.9 % of parents experienced clinically disturbed sleep quality. In terms of the second aim, it was found that parental sleep quality, anxiety, and depression symptoms independently predicted children's overall child health-related quality of life. However, when child variables were considered (consisting of a combination of child sleep, ADHD and autistic characteristics), parental variables were no longer significantly predictive of child health-related quality of life. Rather, the strength of children's co-occurrences significantly predicted health-related quality of life above these parental variables. This suggests that co-occurrences mediate the relationship between parental variables and child health-related quality of life and implies that the perceived contribution of parental variables to child health-related quality of life was an indirect relationship resulting from the impact that child variables have on the parental variables. This extends previous research which has mainly focused on the level of relative contribution of parental variables and epilepsy-specific variables to child health-related quality of life [46,47]. When co-occurrences are considered in relation to child health-related quality of life, they are typically categorised as binary variables rather than being specified individually[48]. These findings have significant clinical utility, as they present evidence for the role of co-occurring conditions in child health-related quality of life, which are often overlooked in the epilepsy care pathway. This study can contribute valuable insights to this changing landscape. Notably, in light of recent initiatives aiming at screening and facilitating onward referral for mental health symptoms in people with epilepsy [49,50].

5.1. Parental mental health symptoms

The current study revealed that parents scored a mean of 8.70 and 4.96 on the anxiety and depression subscales of the HADS respectively. This is similar to another study [51] where parents of CWE scored 8.3 and 6.0 on these subscales. In addition, prevalence rates of parents who scored above the clinical thresholds were calculated, revealing that 33.3 % and 12.1 % of parents scored above the clinical threshold for anxiety and depression symptoms respectively. In comparison to other studies which have used the same measure in parents of CWE, the values within this study are considerably lower. For example, one study [52] found that 55.0 % and 38.7 % and another study [22] found that 58 % and 42 % of parents of CWE scored above the clinical thresholds for anxiety and depression subscales respectively. The differences between the prevalence rates may be explained by various factors. As noted by [22] over 30 % of the CWE sample were suggested to have mental development in the "abnormal" range, but in our study, children with co-occurring ID were excluded. Prior research has found that parents of children with a significant developmental delay or ID experience heightened stress levels [19,53]. This is due to the increased demands required of the parents in their role, due to the need to manage both seizures and

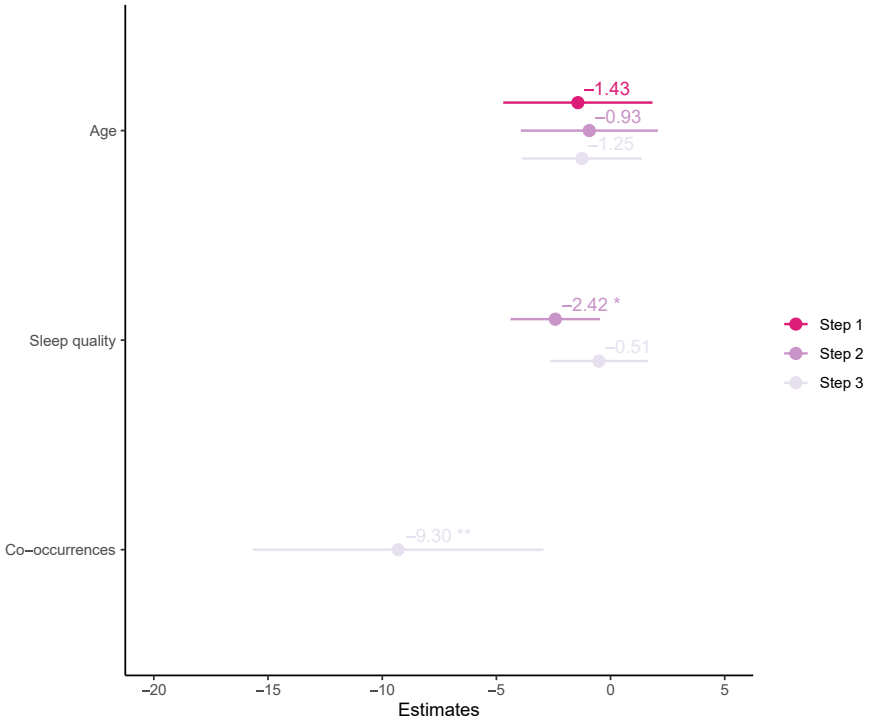

Fig. 2. Regression coefficient plot for hierarchical regression predicting child health-related quality of life from parental sleep quality and child co-occurring conditions. The y axis represents the variables of interest inputted at each step. The x axis represents the strength of the unstandardised beta coefficient estimate. Coefficients from the first model are presented in pink, second model in purple and the third model in lilac. The horizontal line represents the 95 % confident intervals and the circles represent the point estimate of the unstandardised beta coefficients. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

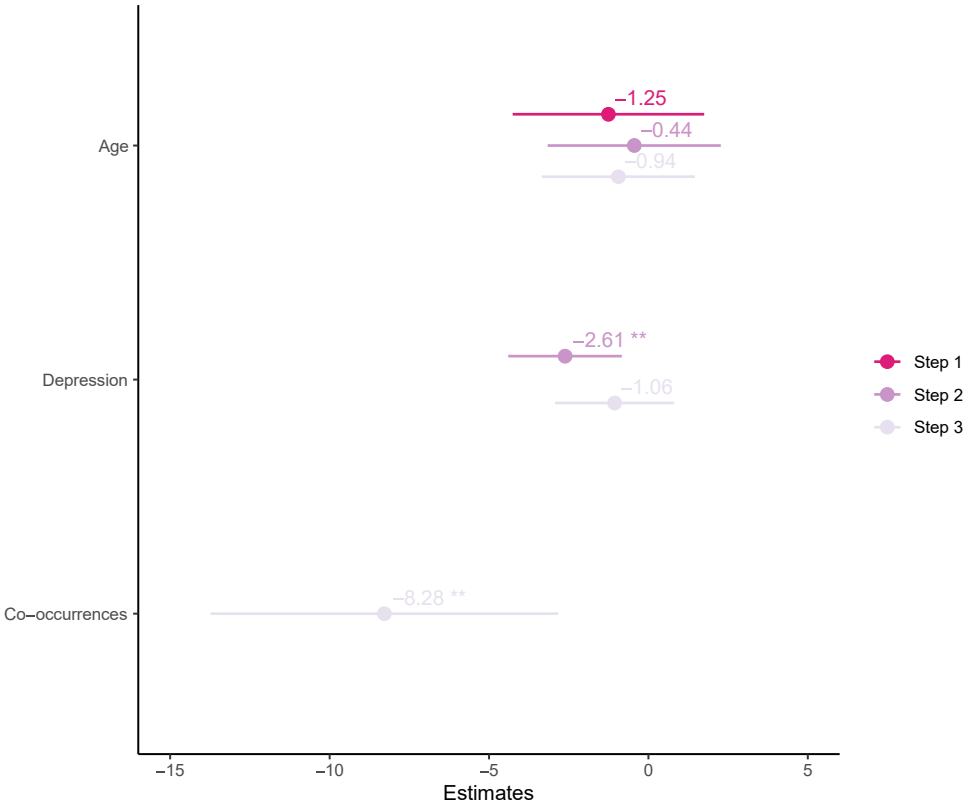

Fig. 3. Regression coefficient plot for hierarchical regression predicting child health-related quality of life from parental depression symptoms and child co-occurring conditions.

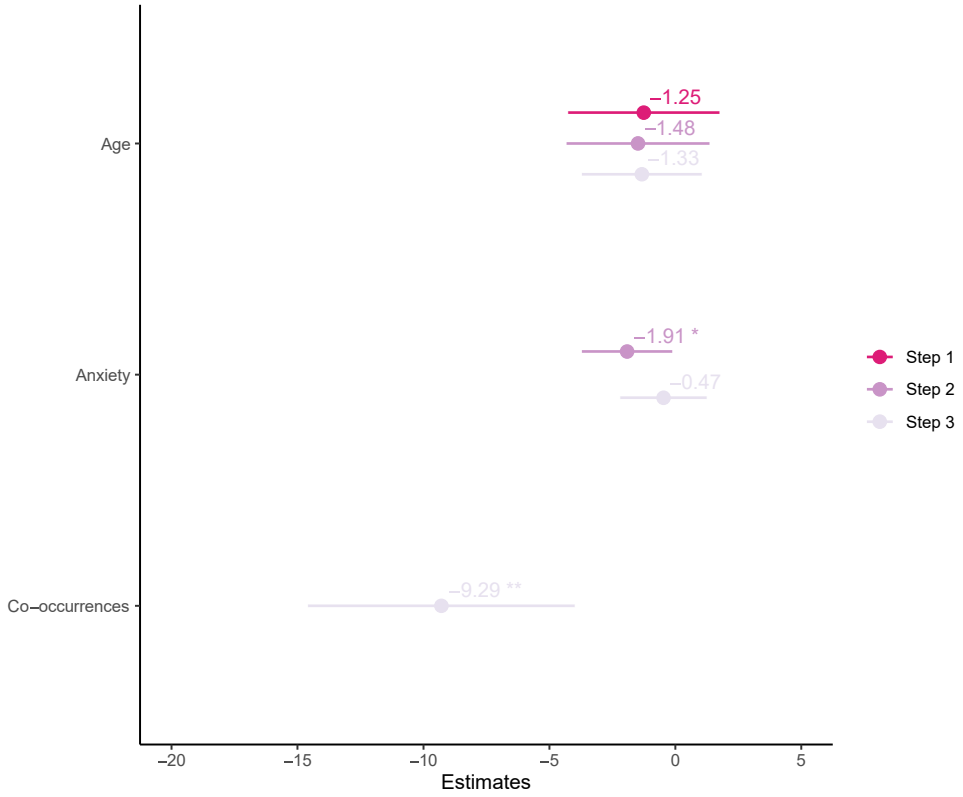

Fig. 4. Regression coefficient plot for hierarchical regression predicting child health-related quality of life from parental anxiety symptoms and child co-occurring conditions.

additional behavioural and cognitive differences [54]. In addition to increased caring responsibilities, co-occurring ID has been found to be associated with higher stigma and poorer child-parent relationship [9]. This has been shown to increase stress in parents [55], which can ultimately contribute to increased risk of psychopathologies such as depression and anxiety.

Despite discrepancies between the rates of mental health symptoms across studies, there were consistencies between studies when observing the difference within anxiety and depression symptoms. Consistent with the findings in the current study, most previous studies indicated that anxiety symptoms were higher than depression symptoms in parents CWE. Higher anxiety symptoms can arise due to the unpredictable and chronic nature of epilepsy [21], which can leave parents in a constant state of worry. Although it was not possible to use a control group within this study, comparison of HADs scores can be made to a similarly aged sample. It was found that 17.3 % of people score above the clinical threshold for anxiety symptoms whereas 7.7 % of people scored above the clinical threshold for depression symptoms [56]. These scores are lower compared than those in the current study and emphasise that parents of CWE are vulnerable to increased mental health difficulties. This emphasises the need to consider these outcomes in the epilepsy management process and to provide suitable support for parents.

5.2. Parental sleep problems

Within this study, the mean total PSQI score (7.46) was consistent with the scores of prior studies (6.3–7.7) that have compared sleep quality in parents of CWE to parents of children without epilepsy [11,57]. Notably two sleep domains (sleep quality and sleep latency) were heightened compared to other scores. Extended sleep latency is consistent with prior research [58]. These disturbances may be due to parental concerns over their children experiencing nocturnal seizures [11]. Such disturbances severely impact parental functioning and their ability to perform their caregiving role [59], which ultimately contributes to poorer QOL in CWE.

In addition, 67.9 % of parents scored above the threshold for sleep quality, a higher percentage compared to previous studies, which have reported poor sleep quality in 37.6 to 59.9 % of parents [25]. In addition, this study revealed that parental sleep quality was significantly associated with parental anxiety symptoms. This is in line with prior research [10,25,57] which have also documented associations between parental wellbeing and sleep. Due to the cross-sectional nature of this study, a causal relationship could not be confirmed. However, the majority of research indicates that this association is likely to be bidirectional [60]. Sleep problems may be a symptom of poor emotional functioning, preventing parents from being able to settle at the onset of sleep. Conversely, sleep problems in parents may exacerbate emotional problems such as stress and depression [12,57]. These findings require clinical acknowledgement, given that sleep disturbances are also known to contribute significantly to physical health outcomes in parents of CWE [61].

5.3. Contribution of parental mental health and sleep quality to child health-related quality of life

The results of this study indicated that parental anxiety, depression, and sleep quality were initially all significantly predictive of child health-related quality of life. Consistent with this finding, prior studies have found that parental mental health is strongly associated with health-related quality of life in CWE [20,21,62]. One possible explanation is that parents are concerned about their child's epilepsy and their inability to control the seizures can shape their parenting behaviours [21], such as imposing excessive restrictions on their child's everyday activities [20,55]. It is important to recognise that informant-reports of child health-related quality of life have been criticised in prior research, as negative emotions including anxiety and depression symptoms can

influence parents' reporting [63,64]. Nevertheless, research has demonstrated a relationship between parental mental health and adolescents' self-report of health-related quality of life [65] The current study also revealed that parental sleep quality was significantly predictive of child health-related quality of life. This relationship may arise due to the impact of poor sleep on parental functioning, reducing their ability to provide optimal support for their child's needs. To date, there is no research which has focused on the association between parental sleep and health-related quality of life in children. A possible reason for the lack of research is that poor sleep quality may be masked by symptoms of anxiety and depression, thus exerting an indirect association with child health-related quality of life, which is not captured. Despite this, the potential indirect impact of poor sleep on child health-related quality of life is demonstrated by previous studies. One study found that poor parental sleep quality was negatively associated with parent's ability to cope with their child's disease [24]. This is also emphasised by a study which found that children's perception of their health-related quality of life was related to parents' ability to support their needs [13]. Overall, these findings expand on current literature and point towards the need to better understand the impact of parental variables compared to child variables in determining child health-related quality of life.

5.4. Contribution of parental variables vs child co-occurrences to child health-related quality of life

When child co-occurring variables (i.e., component 1 of the PCA, including child sleep, ADHD and autistic characteristics) were considered in association with parental variables (sleep quality, anxiety, and depression symptoms), the analysis suggested that they mediate the relationship between parental variables and child health-related quality of life. The strong role of co-occurrences in predicting child health-related quality of life above parental variables is supported by prior research [31]. The role of co-occurring conditions in predicting parental variables and child health-related quality of life may reflect the lack of support parents receive for supporting their child's co-occurring conditions and traits. Outcomes focused on epilepsy-specific variables are routinely addressed in clinical practice. However, this leaves co-occurrences such as sleep problems and neurodevelopmental characteristics vulnerable to diagnostic overshadowing, whereby they may be attributed to side effects of ASMs or effects of seizures [66]. Co-occurrences can have direct and significant impact on various aspects of children's functioning [1,67]. If left unaddressed, they can also lead to additional strain on parental wellbeing and sleep. Similarly, they can also leave parents feeling unsupported in their role and vulnerable to negative emotions [55]. Nevertheless, it is important to note that these findings do not undermine the influence or importance of parental variables, as a mediation analysis could not be conducted to confirm this relationship directly, due to the small sample size. Rather parental variables still needed to be considered in epilepsy management to maximise the well-being of the whole family [68].

5.5. Limitations

There are several limitations that must be considered when interpreting these findings. Due to the small sample size, all child variables could not be inputted into the regression alongside the parental variables. Therefore, a PCA was used to create a composite index measure for child variables. As a result, the effect of individual variables within this composite could not be separated out. In addition, standard component selection criteria indicated that only one component should be retained, which did not include any epilepsy-specific information. However, this limitation does not affect the results greatly given that all three of the included child variables often co-occur in CWE and CWOE [69–71] and it is therefore reasonable to assume that intervening with one can contribute to improvements in the others. The lack of inclusion of epilepsy-specific variables as predictors of child health-related quality of life is unlikely to impact our current findings as previous analysis has suggested that there are commonalities across epilepsy types, and that child health-related quality of life is not strongly impacted by epilepsy specific variables [1,31]. This includes SELECTS, which has historically been considered a more benign form of epilepsy and is associated with a relatively low seizure burden. However, larger studies will be needed to confirm these observations. Another caveat is that although the results revealed poor sleep quality and heightened anxiety and depression symptoms in parents, the cross-sectional nature of the study means that cause and effect cannot be inferred. Gaining information on parental mental health or sleep history could shed light on the direction of this relationship. Additionally, incorporating more detailed measures related to family households could help clarify the influence of other confounding factors on the relationship between parental variables and HRQOL.

A dimensional approach was taken to examine autistic and ADHD characteristics, which are not clinical diagnoses thus may better reflect traits, acknowledging that not all children scored above threshold. A dimensional approach was necessary to extend the limited evidence base available on the contribution of neurodevelopmental conditions on health-related quality of life. Various studies outline that although ADHD and autism are prevalent in CWE, they continue to be underdiagnosed in this group [72,73], with diagnoses often occurring later in their developmental trajectory compared to CWOE [74]. Therefore, these undiagnosed conditions could significantly influence the health-related quality of life in CWE.

6. Conclusion

This study confirms the need for assessment and support of co-occurring conditions in CWE. The results demonstrated that parents of CWE are at risk of poor mental health and sleep quality. However, whilst parental variables were initially predictive of health-related quality of life, their effect was not retained following inclusion of child co-occurrences. Therefore, future research should aim to develop further understanding of these relationships with a focus on intervening with co-occurrences, which may ultimately improve the relationship between parental outcomes and child health-related quality of life.

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CRediT authorship contribution statement

Alice A. Winsor: Writing – review & editing, Writing – original draft, Visualization, Software, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Caroline Richards:** Writing – review & editing, Validation, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Conceptualization. **Stefano Seri:** Writing – review & editing, Validation, Supervision, Resources, Investigation. **Ashley Liew:** Writing – review & editing, Investigation. **Andrew P. Bagshaw:** Writing – review & editing, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization.

Declaration of competing interest

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

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Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2024.109941.

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