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Maternal and paternal quality of life in children with epilepsy: Who is affected more?

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ABSTRACT

Introduction: This study aimed to evaluate and compare parental quality of life (QoL), anxiety, and depression in mothers and fathers of children with epilepsy (CWE).
Material and methods: Thirty-three mothers and 33 fathers of 33 CWE (aged 1–16 years) completed the World Health Organization Quality of Life–Brief Form (WHOQOL-BREF), Beck Depression Inventory (BDI), and Beck Anxiety Inventory (BAI) questionnaires. Scores for the questionnaires were compared for 36 mothers and 36 fathers of 36 healthy children (aged 1–16 years). The control group consisted of hospital staff who had healthy children.
Results: Mothers of CWE had significantly lower scores for the environmental domain of the WHOQOL-BREF, BDI, and BAI questionnaires compared with mothers of healthy children ($p < 0.05$), while fathers showed no significant difference ($p > 0.05$). Furthermore, mothers of CWE had significantly lower scores for the psychological domain of the WHOQOL-BREF compared with fathers ($p < 0.05$). The environmental domain of the WHOQOL-BREF questionnaire was negatively correlated with the number of children for all parents ($r = -0.342$, $p = 0.005$), and the BAI and BDI scales were positively correlated with the number of children ($r = 0.386$, $p = 0.001$; $r = 0.395$, $p = 0.001$, respectively).
Conclusion: Mothers of CWE showed lower scores for the psychological domain in QoL analysis compared with fathers of CWE, as well as decreased emotional wellbeing and lower QoL compared with mothers of healthy children. These results reveal that parents of CWE with a larger family size are more affected and that mothers of CWE are more affected. The reasons for these findings and possible interventions that might improve QoL, particularly in mothers with CWE, require further research.

1. Introduction

In Turkey, the prevalence of epilepsy is 7–12.2 per 1000 in the general population and 0.8% in children [1–5]. These results were higher than in developed countries, suggesting that the number of children and parents coping with epilepsy is greater in Turkey than in developed countries [6]. According to the Turkish Statistical Institute, in 2017, there were 19 million children between the ages of 0 and 14 years, and there were approximately 152,000 children and 304,000 parents coping with epilepsy in Turkey, indicating that this is a significant public health problem [7]. The nature of seizures in children often makes the parents more anxious than the patients themselves, as patients having seizures with impaired awareness are not aware of their seizures. Epileptic seizures often occur without warning and may lead to embarrassing and dangerous circumstances [8]. For children with epilepsy (CWE) and their parents, epilepsy is not just a medical condition but also a social issue [9].

Many studies have reported that CWE have a higher rate of psychological disturbance than healthy children or children with other chronic illnesses [10]; CWE may feel ashamed about their epilepsy, and parental overprotection may play a role in this feeling and may be associated with behavioral problems later [11]. Furthermore, parental attitudes significantly affect quality of life (QoL), not only in the children but also in the parents themselves. Parents generally worry that seizures will harm their children, and this affects their QoL [12]. Parental anxiety and QoL may affect the QoL of CWE, and vice versa. Furthermore, the severity of epilepsy may affect parental QoL [13]. In families of CWE, greater stress, poorer quality of parent–child relationships, and lower parenting confidence have been found [14,15]. Other parameters also affect QoL, such as employment; typical female employment was 37.6% in Turkey in 2017 [16].

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The majority of studies on epilepsy have focused on mothers and relied on them to report on the impact on the entire family [8,13,15,17]. The aim of the present study was to evaluate the relationship between the severity of seizures and parental anxiety and QoL, and to determine who is more affected, the mother or the father, which is an area of research that has been neglected and warrants further research. Parents of healthy children were assigned as a control group, because the main purpose of this study was to evaluate the QoL measures of parents (both and individually) of CWE versus those of healthy children.

2. Methods and materials

2.1. Participants

Participants included consecutive parents of CWE between the ages of 1 and 16 years, who were treated in the Gulhane Medical Faculty Pediatric Neurology Unit for epilepsy for at least one year between January and May 2009 [13]. Parents with children without chronic disease history between the ages of 1 and 16 years were enrolled in the study as a control group. One in each pair of parents in the control group was hospital staff, because we could not find healthy children in the pediatric neurology unit. The study was designed to enroll both parents. Parents were simultaneously recruited just after their child's visit. There were no exclusions from the study. Seizure control was classified as seizure-free (no seizure for at least 24 months), no seizure for the past six months, no more than one seizure per month, no more than two to three seizures per month, and daily or weekly seizures. All interviews were conducted by the first author.

2.2. Procedures

The study was approved by the local ethics committee. Written permission was obtained from the parents who agreed to participate in the study. At the time of the neurology outpatient visit, sociodemographic, seizure type, and severity information were obtained, and the Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), and World Health Organization Quality of Life–Brief Form (WHOQOL-BREF) questionnaires were completed by both parents.

2.3. Instruments

2.3.1. WHOQOL-BREF

The WHOQOL-BREF is a 26-item questionnaire that assesses QoL in individuals. The questionnaire is a generic instrument designed to be applicable to individuals living under different circumstances and cultures [18,19]. The WHOQOL describes QoL as a multidimensional concept. There are two versions: one is the full WHOQOL with 100 items, and the other is a short version, known as the WHOQOL-BREF, with 26 items. The WHOQOL-BREF is a valid and reliable alternative to the full version and is useful in clinical evaluations [18,19]. Four domains can be obtained: physical, psychological, social relationship, and environmental. The physical part evaluates daily activities, treatment compliance, pain, sleep, energy, and fatigue. The psychological part evaluates positive and negative feelings, self-esteem, physical appearance, and personal beliefs. The social relationship part includes personal relationships, social support, and sexual activity. The environmental part evaluates security and safety, financial situation, and social care. The questionnaire is scored from 1 to 5, in which higher scores indicate a better QoL [20]. The Turkish version of the WHOQOL-BREF (TR) was found to be highly satisfactory regarding internal consistency, reliability, and construct validity [21].

2.3.2. Beck depression inventory

The BDI is a 21-item survey designed to measure somatic and cognitive–affective symptoms of depression [22]. Higher scores show more severe depression. The standard cutoff scores are as follows: 0–9 indicates minimal depression; 10–18 indicates mild depression; 19–29 indicates moderate depression; and 30–63 indicates severe depression. The validity and reliability of the BDI in the Turkish population were demonstrated by Hisli et al. [23].

2.3.3. Beck anxiety inventory

The BAI was designed to measure the presence and intensity of anxiety symptoms [22]. The total score ranges from 0 to 63. Scores of 0–9 indicate normal or no anxiety, 10–18 mild to moderate anxiety, 19–29 moderate to severe anxiety, and 30–63 severe anxiety. The validity and reliability of the BAI in the Turkish population were demonstrated by Ulusoy et al. [24].

2.4. Covariates

Other covariates besides the BDI and BAI included the severity of the comorbid condition, seizure control, duration of diagnosis, number of antiepileptic drugs (AEDs), magnetic resonance imaging (MRI), electroencephalogram (EEG), gender, age, and number of siblings of the child. The MRI findings were divided into normal or abnormal, and EEG results were divided into three categories as specific epileptiform discharges, nonspecific abnormalities such as slow wave, and normal EEG findings. Comorbid condition severity was based on four categories: children with no other diagnosed conditions, children with diagnosed mild behavioral problems and difficulty learning, children with moderate problems who require significant interventions within the school setting, and children with severe disabilities that significantly interfere with ambulation and communication [13].

2.5. Statistical analysis

The variables were investigated using visual (histograms) and analytical methods (Kolmogorov–Smirnov) to determine normal distribution. The QoL, BAI, and BDI scores were compared using the Mann–Whitney *U* test between the fathers and mothers of CWE and controls. The Kruskal–Wallis test was used for multiple comparisons. The data were represented as a median (minimum–maximum) for parameters that were not normally distributed. Chi-square analysis was used to compare the proportions. The Spearman correlation test was used to evaluate the correlation between QoL and illness-related characteristics of CWE. When investigating the changes in the environmental domain of QoL by groups, the effect of education was adjusted using the analysis of covariance (ANCOVA) test. Statistical analyses were performed with Statistical Package for the Social Sciences (SPSS) 23.0 (IBM, Chicago, Illinois, USA). A p value of <0.05 was considered statistically significant.

3. Results

3.1. Sociodemographic data

There were 66 parents in the group of parents of CWE and 72 parents in the group of parents of healthy children, with mean ages of 37.45 ± 5.70 and 37.08 ± 4.96 years, respectively, and no significant difference ($p = 0.68$). Educational characteristics were different between the groups; in parents of CWE, 48.5% graduated from primary school, 30.3% from high school, and 21.2% from university, while in parents of healthy children these values were 2.8%, 8.3%, and 88.9%, respectively ($p < 0.001$). In parents of CWE, the percentages of fathers graduating from primary school were 15.2%, high school 39.4%, and university 45.0%, while in parents of healthy children these values were 2.8%, 25%, and 72.2%, respectively ($p = 0.04$). In parents of CWE, for mothers, 16 (48.5%) graduated from primary school, 10 (30.3%) from high school, and seven (21.2%) from university, while in parents with healthy children these values were one (2.8%), three (8.3%), and 32 (88.9%), respectively ($p < 0.001$). There was no correlation between the age of parents and all domains of the WHOQOL-BREF ($p > 0.05$).

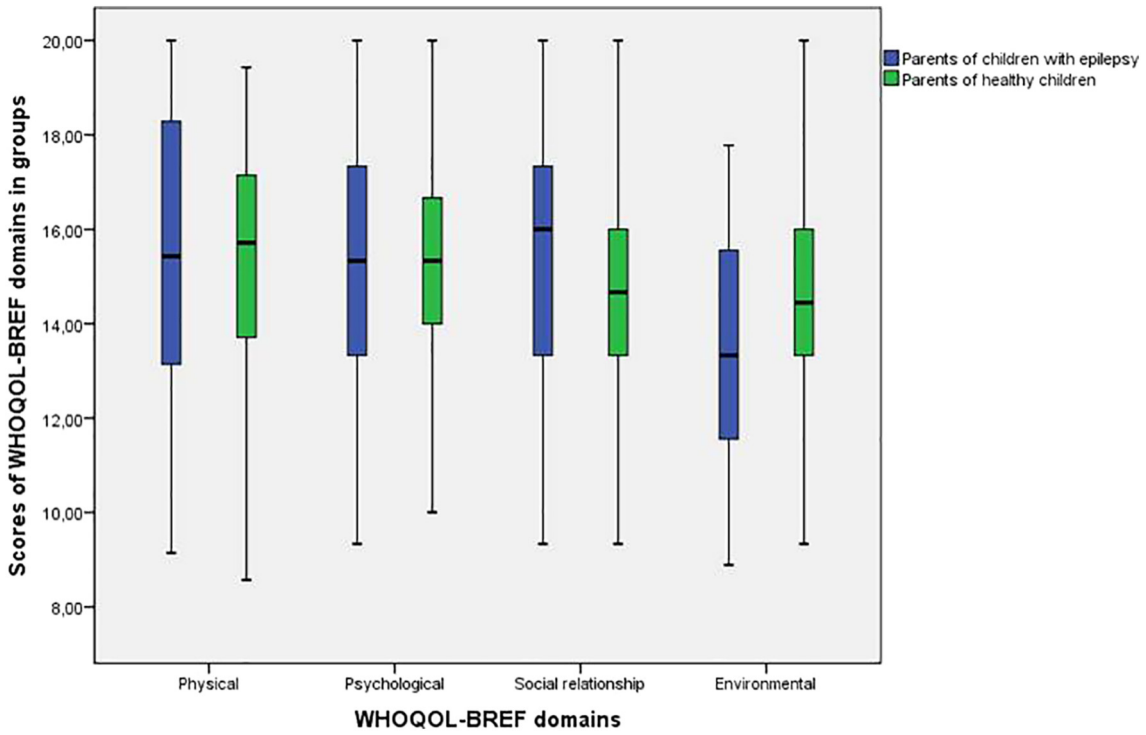

Fig. 1. Median values of WHOQOL-BREF (TR) version scores on Physical, Psychological, Social Relationship, and Environmental domains among parents of children with epilepsy and healthy subjects.

3.2. Quality of life

Parents of CWE had lower scores than parents of healthy children according to the environmental domain of the WHOQOL-BREF, with scores of 13.33 (8.89–17.78) and 14.44 (7.56–20), respectively (p = 0.02). The other domains were not statistically different between the groups (Fig. 1). Table 1 shows the median scores for the different domains between the groups. In parents of CWE, mothers had lower scores than fathers for the psychological domain, with scores of 14.66 (10–18.67) and 15.33 (9.14–18.86), respectively (0.01). The other domains were not statistically different between the genders (Table 2, Fig. 2).

When mothers were compared between the groups, mothers of CWE were found to have lower environmental domains than mothers of healthy children. The environmental domain was 12.88 (8.89–17.78) compared with 14.66 (11.56–17.78), respectively (p = 0.02, Fig. 3). The environmental domain was 13.77 (8.89–17.339) in fathers of CWE compared with 14.22 (7.56–20) in fathers of healthy children (p = 0.42). The other domains were not statistically different between mothers of CWE and mothers of healthy children or between fathers of CWE and fathers of healthy children (Tables 3 and 4). In addition, the environmental domain of the WHOQOL-BREF was not different according to education in mothers (p = 0.327). When investigating the changes in the environmental domain of the WHOQOL-BREF in mothers between the groups, the effects of education were adjusted using the ANCOVA test, and there was still a statistically significant difference (adjusted p value = 0.037).

3.3. Depression and anxiety scales

The depression scales for the BAI and BDI showed that both scores were higher in parents of CWE compared with parents of healthy children (BAI, 10 [0–53] vs 6 [0–46] p = 0.002; BDI, 10 [0–37] vs 6 [0–37] p = 0.002, respectively, Table 1). However, when subgroup analyses were applied according to gender, mothers had statistically significantly higher scores in parents of CWE compared with parents of healthy children (BAI, 11 [1–38] vs 8 [0–31] p = 0.004; BDI, 11 [0–37] vs 6.5 [0–15] p = 0.004, respectively, Table 3). Scores for fathers were not different (BAI, 9 [0–53] vs 5 [0–46] p = 0.10; BDI, 9 [0–28] vs 5 [0–37] p = 0.16,

Table 1
Comparison of World Health Organization Quality of Life–Brief Form–Turkish version scores on Physical, Psychological, Social Relationship, and Environmental domains among parents of children with epilepsy (CWE) and healthy subjects.

	Parents of CWE N = 66	Parents of healthy children N = 72	p value
Physical (median, min-max)	15.42 (9.14–20)	17.71 (8.57–19.43)	0.70
Psychological (median, min-max)	15.33 (9.33–20)	15.33 (8.67–20)	0.80
Social relationship (median, min-max)	16 (9.33–20)	14.66 (8–20)	0.24
Environmental (median, min-max)	13.33 (8.89–17.78)	14.44 (7.56–20)	0.02
Beck depression	10 (0–37)	6 (0–37)	0.002
Beck anxiety	10 (0–53)	6 (0–46)	0.002

Table 2
Comparison of World Health Organization Quality of Life–Brief Form–Turkish version scores on Physical, Psychological, Social Relationship, and Environmental domains among parents of children with epilepsy according to gender.

	Mothers N = 33	Fathers N = 33	p value
Physical (median, min-max)	14.85 (10.29–20)	15.42 (9.14–18.86)	0.84
Psychological (median, min-max)	14.66 (10–18.67)	15.33 (9.33–20)	0.01
Social relationship (median, min-max)	16 (9.33–18.67)	16 (10.67–20)	0.60
Environmental (median, min-max)	12.88 (8.89–17.78)	13.77 (8.89–17.33)	0.38
Beck depression	11 (0–37)	9 (0–28)	0.19
Beck anxiety	11 (1–38)	9 (0–53)	0.09

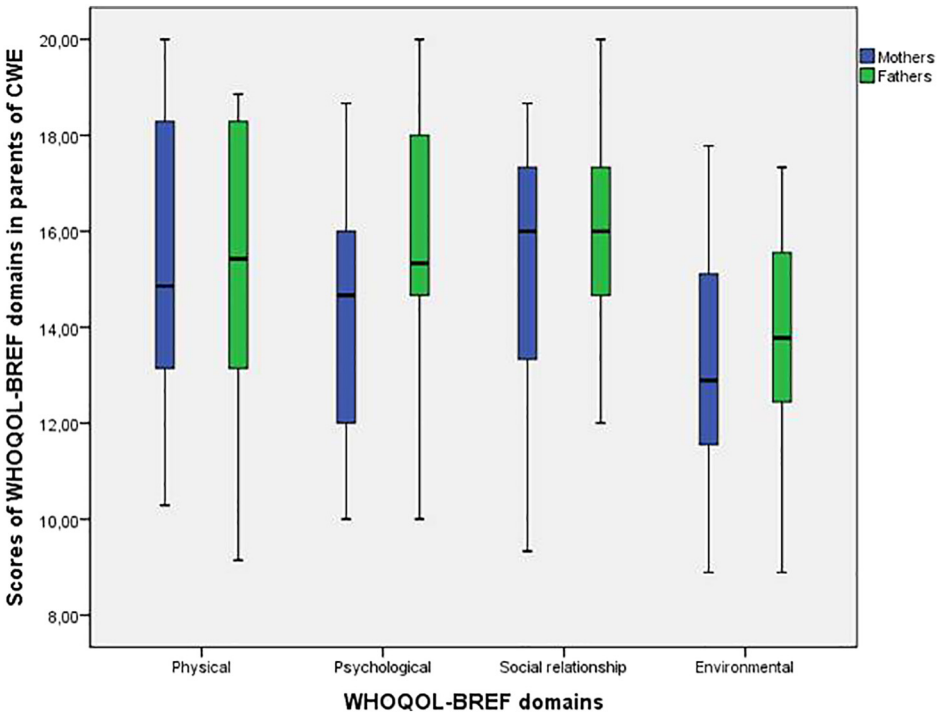

Fig. 2. Median values of WHOQOL-BREF (TR) version scores on Physical, Psychological, Social Relationship, and Environmental domains among mothers and fathers of children with epilepsy.

respectively, Table 4). In parents of CWE, these scores were not different between mothers and fathers (BAI, 11 [1–38] vs 9 [0–53] $p = 0.09$; BDI, 11 [0–37] vs 9 [0–28] $p = 0.19$, respectively, Table 2). There was no correlation between education level and BDI or BAI scores ($p = 0.81$ and $p = 0.70$, respectively), and there was no difference in BDI or BAI scores according to education level ($p = 0.80$ and $p = 0.78$, respectively) in parents of CWE.

3.4. Illness-related characteristics of CWE

The demographics and clinical background of the CWE are presented in Table 5. There were no differences or correlations between the WHOQOL-BREF domains according to type of epilepsy, control of seizures, duration of epilepsy, comorbidity situation, occurrence of status epilepticus, number of drugs used, or MRI and EEG findings. However, there was

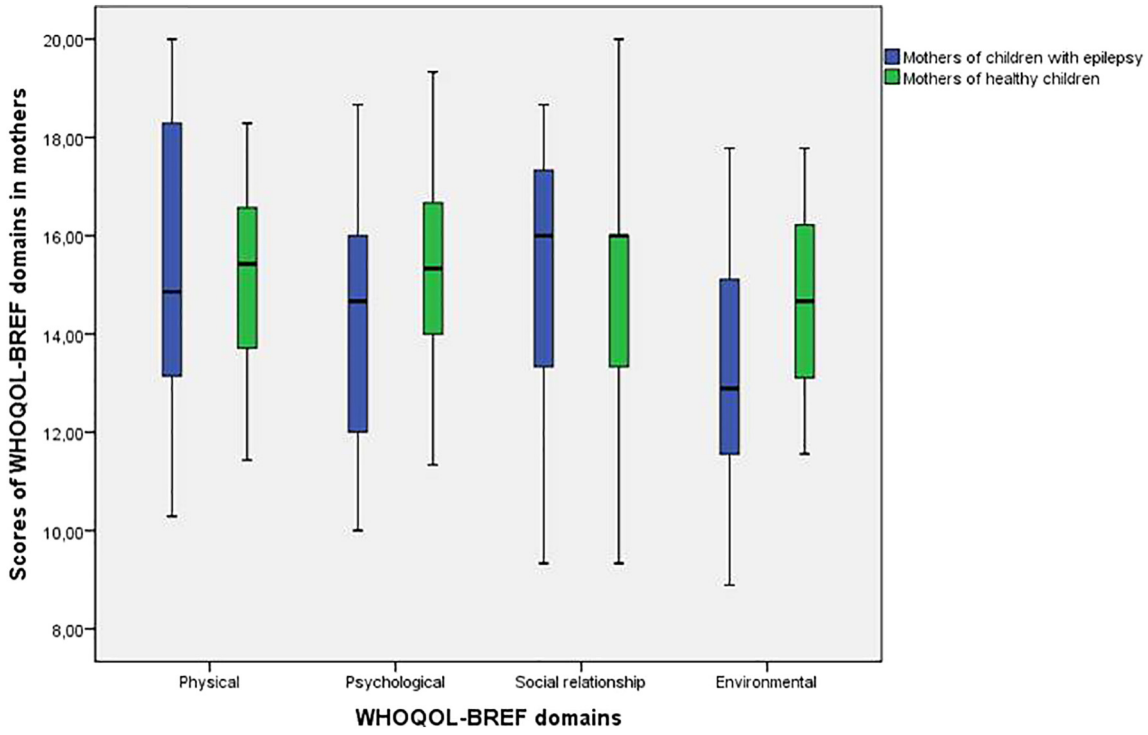

Fig. 3. Median values of WHOQOL-BREF (TR) version scores on Physical, Psychological, Social Relationship, and Environmental domains among mothers of children with epilepsy and healthy subjects.

Table 3
Comparison of World Health Organization Quality of Life–Brief Form–Turkish version scores on Physical, Psychological, Social Relationship, and Environmental domains among mothers of children with epilepsy (CWE) and healthy subjects.

	Mothers of CWE N = 33	Mothers of healthy children N = 36	p value
Physical (median, min-max)	14.85 (10.29–20)	15.42 (11.43–18.29)	0.89
Psychological (median, min-max)	14.66 (10–18.67)	15.33 (11.33–19.33)	0.05
Social relationship (median, min-max)	16 (9.33–18.67)	16 (9.33–20)	0.57
Environmental (median, min-max)	12.88 (8.89–17.78)	14.66 (11.56–17.78)	0.02
Beck Depression	11 (0–37)	6.5 (0–15)	0.004
Beck Anxiety	11 (1–38)	8 (0–31)	0.004

a negative correlation between the number of children and the physical and psychological domains of the WHOQOL-BREF for fathers ($r = -0.404$, $p = 0.02$; $r = -0.421$, $p = 0.01$, respectively). Furthermore, the environmental domain of the WHOQOL-BREF and the number of children were negatively correlated for all parents ($r = -0.342$, $p = 0.005$). Moreover, the BAI and BDI scales were correlated with the number of children ($r = 0.386$, $p = 0.001$; $r = 0.395$, $p = 0.001$, respectively).

4. Discussion

The main finding of this study was that the group of parents with CWE showed lower scores for the environmental domain compared with the control group, especially in mothers, while the other domains were not different between the groups. This finding suggests that the parents of CWE cope with epilepsy in terms of physical, psychological, and social relationship domains, but they have problems in the environmental domain, which involves physical security and safety, financial resources, opportunities for acquiring information and skills, participation in and opportunities for recreation, leisure and transport, home environment, access to health and social care and their availability, and physical environment. Parents of CWE in this study had the opportunity to access health and social care. Ferro et al. suggested that a supportive environment for parents and their CWE may improve the QoL of CWE [25]. We suggest that environmental support may also improve the QoL of parents of CWE.

When subgroup analysis was applied, this difference was found in mothers, but not in fathers. This reveals that the mothers of CWE do not feel that they have enough environmental support, while fathers have no problem with this situation. Lower educational characteristics in mothers of CWE compared with mothers of healthy children could have played a role in the lower environmental domain; however, we investigated the changes in the environmental domain of the WHOQOL-BREF between the groups; the effects of education were adjusted using covariance analysis, and there was still a statistically significant difference (adjusted p value = 0.037), which showed that education did not have an effect on the environmental domain of the WHOQOL-BREF in our sample. Also, we did not find any effect of education on anxiety or depression scales in parents of CWE. Fathers also had the same difference in the educational characteristic but showed no differences in the environmental domain. Puka et al. reported baseline and 10-year follow-up data for 159 mothers of CWE and found that better family resources were associated with the physical health component of health-related QoL at baseline but not after 10-year follow-up [17]. Lv et al. investigated 263 parents of CWE and did not find a correlation between QoL and education or household income [8]. In addition, Huang et al. investigated factors associated with QoL among 3163 married women in China using the WHOQOL-BREF scale. They found statistically significant differences according to monthly income in the physical, psychological, and social relationship domains of the WHOQOL-BREF but not in the environmental domain. They separated education level into two categories: primary school and below and junior high school and above. They did not find any difference in any domain of the WHOQOL-BREF according to education [26].

Puka et al. conducted a systematic review of QoL in parents of CWE and stated that the majority of QoL studies focused on mothers and only three studies focused on fathers [15]. In three European studies, mothers of CWE were found to have lower QoL relative to fathers [15, 27–29]. An Asian study by Lv et al. failed to find a difference in QoL according to the gender of the parents [8]. In Turkey, we found mothers of CWE had lower QoL compared with fathers and mothers of healthy children. These results are important and reflect the effect of cultural differences on QOL among nationalities. Lv et al. found lower QoL (all subscales of SF-36) and increased depression and anxiety in parents of CWE compared with controls. They separated the groups with well-controlled from poorly controlled epilepsy according to the severity of epileptic seizures. Poorly controlled epilepsy was defined as failing more than two AEDs for lack of efficacy and having seizures at least every three months over

Table 4
Comparison of World Health Organization Quality of Life–Brief Form–Turkish version scores on Physical, Psychological, Social Relationship and, Environmental domains among fathers of children with epilepsy (CWE) and healthy subjects.

	Fathers of CWE N = 33	Fathers of healthy children N = 36	p value
Physical (median, min-max)	15.42 (9.14–18.86)	16 (8.57–19.43)	0.60
Psychological (median, min-max)	15.33 (9.33–20)	15.33 (8.67–20)	0.15
Social relationship (median, min-max)	16 (10.67–20)	14.66 (8–20)	0.26
Environmental (median, min-max)	13.77 (8.89–17.339)	14.22 (7.56–20)	0.42
Beck depression	9 (0–28)	5 (0–37)	0.16
Beck anxiety	9 (0–53)	5 (0–46)	0.10

Table 5
Demographic and illness-related characteristics of children with epilepsy.

Number of children	33
Gender of children (F/M)	**(15/18)**
Age of child, years (Median; minimum-maximum)	9 (1–16)
Age at onset epilepsy, years (Median; minimum-maximum)	4 (0.5–15)
Duration of epilepsy, years (Median; minimum-maximum)	3.5 (1–13)
Number of drugs (Median; minimum-maximum)	1 (1–2)
Seizure type n (%)	
Focal	16 (48.5)
Generalized	17 (51.5)
Seizure control n (%)	
Seizure-free >2 years	15 (45.5)
No seizure for past six months	8 (24.2)
≤1seizure per month	4 (12.1)
>1 seizure per month	2 (6.1)
Daily or weekly seizure	4 (12.1)
Status epilepticus n (%)	
Yes	2 (6.1)
No	31 (93.9)
Comorbidity n (%)	
No	29 (87.9)
Mild	4 (12.1)
Moderate	0 (0)
MRI n (%)	
Normal	31 (93.9)
Abnormal	2 (6.1)
EEG n (%)	
Normal	19 (57.6)
Nonspecific abnormality	5 (15.2)
Epileptiform abnormality	9 (27.2)
Number of children in the family (including a child with epilepsy and spouses) (Median; minimum-maximum)	2 (1–4)

the past year, and the authors found that the well-controlled epilepsy had a better QoL [8]. Bompori et al. found that the parents of children with accompanying neurodevelopmental problems and resistant epilepsy had poorer QoL compared with parents of healthy children, regardless of gender [30]. Akvardar et al. found no interactions between gender and QoL when evaluating the Turkish version of the WHOQOL-BREF in healthy participants as well as psychiatric patients and patients with diabetes [20]. We did not find any difference in control of seizures in parents of CWE. This may be due to the fact that most CWE had good seizure control and were without comorbidity in our study.

Increased anxiety and depression were found in mothers of CWE compared with mothers of healthy children, but there was no difference between the fathers. We also found that mothers of CWE had lower scores in the psychological domain of the WHOQOL-BREF compared with fathers. These results suggest that mothers are more affected by their children's disease. Furthermore, mothers were previously found to have greater care burden than fathers for CWE [31].

Jones and Reilly published a systematic review of the parental anxiety of childhood epilepsy and found three studies that considered parental gender [32]. Wotjas et al. reported higher anxiety scores in mothers compared with fathers [33], and Lewis et al. also found higher levels of anxiety in mothers, but did not report the statistical significance [34]. Adewuya found no difference between mothers and fathers of CWE among depression and anxiety. However, the number of fathers ($n = 5$) was very low compared with that of mothers ($n = 81$) in that study. Additionally, maternal depression and maternal psychopathology, as well as the number and side effects of AEDs and duration of illness, were shown to be associated with poor overall QoL in adolescents with epilepsy [35]. Williams et al. found that increased anxiety in parents was associated with QoL in children but did not find a difference between seizure type and QoL, except for mixed seizure types. Moreover, the authors investigated parental anxiety and QoL in children, not QoL in parents [13]. Cushner-Weinstein et al. also found high levels of stress in parents of CWE, but they did not find a relationship between parental stress and seizure-related variables such as seizure frequency, seizure type, or duration of disorders, and they did not evaluate QoL in parents [36].

The current literature shows no association between parental QOL and the age of children, seizure onset age, or number of AEDs [8,15,17,37,38]. We did not find any association between parental QoL and child seizure type, duration, control, or number of AEDs, but we did find that an increased number of children in the family is associated with higher anxiety and depression, as well as the environmental domain of the WHOQOL-BREF, suggesting that the increased burden of livelihood affects these parameters in parents.

The limitations of this study include a limited number of samples. We evaluated only QoL in parents, not in children. A cross-sectional study design was used, but a lack of longitudinal data means only associations can be reported, not relationships. Moreover, another limitation is the wide age range. Each pediatric age group has different burden-of-care difficulties on its own, but age differentiation was not evaluated in this study.

5. Conclusion

We aimed to evaluate the effect of childhood epilepsy on parental QoL. A major strength of this study is that it compares mothers and fathers in relation to QoL impact. Our findings support previous findings that mothers are more affected by fathers in European studies, although this differed in one Asian study [15]. These results demonstrate that mothers of CWE need more attention than fathers. Parents with a higher number of children are at risk in lower environmental domain scores of the WHOQOL-BREF as well as in higher BAI and BDI scales, and fathers with a higher number of children are at risk in the physical and psychological domains of the WHOQOL-BREF. There are very limited data about mother–father of CWE comparisons, and future studies with larger numbers and different cultures will be useful to determine mother–father differences between epilepsy and control groups.

Conflicts of interest

Authors do not have any conflict of interest.

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