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Quality of life of families and mothers of children with cerebral palsy, with or without epilepsy

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Abstract

Aim: The effects of the presence of epilepsy in Cerebral palsy (CP) on the quality of life (QOL) of mothers and their families are not clear. In this regard, our study aimed to evaluate the effects of the presence of epilepsy in CP on the QOL of mothers and families.

Material and Methods: The study was conducted with 61 mothers whose children had CP, and 25 mothers with healthy children as the control group. Mothers whose children had CP were divided into two groups: children with epilepsy (n = 22) and children without epilepsy (n = 39). All mothers assessed their QOL using the Short Form-36 (SF-36) questionnaire, and their family life qualities were assessed with the Beach Center Family Quality of Life (BC-FQOL) scale.

Results: Despite the fact that mothers of children with CP had the lowest scores on the SF-36 for the physical component summary (PCS) and for the mental component summary (MCS) scores compared with the epilepsy group, there was no significant difference between the groups ($p > 0.05$). In the BC-FQOL, emotional well-being and disability-related support scores were significantly lower in the epilepsy group ($p < 0.05$).

Discussion: Mothers of epileptic children with CP have a worse QOL tendency in both physical and mental health, but there is no significant difference compared to the other mothers.

Keywords

Cerebral palsy; Rehabilitation; Epilepsy; Quality of life; Family; Mother

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Introduction

Cerebral palsy (CP) is a non-progressive persistent movement and postural disorder that occurs as a result of the development of static lesion in the central nervous system (CNS) [1].

Functional inadequacies due to the clinical problems in children with CP can negatively affect children with CP and their families. The nature of this disease and the accompanying conditions affecting the quality of life (QOL), and the QOL of the mother and the family, as well as child, have been the subject of research in recent years [2].

A child with CP can be perceived as a big disappointment in the family, may be considered as a reason why the family suffers more, and can increase anxiety levels of parents. This greatly affects the psychological, social, economic and cultural life of the family [3,4]. It has been suggested that stress associated with coping with chronic illnesses is a primary risk factor for the development of psychosocial problems for both the affected child and the family [5]. The influence of CP on the daily life of the family and caregiver depends on various factors, such as the type and severity of CP, the presence of additional clinical problems such as epilepsy, the level of family and community support, family economic structure, socio-cultural level, and the educational status [2,5].

CP is not a specific disease, but a collection of symptoms. In addition to behavioral and cognitive problems, as well as motor dysfunction in CP, epilepsy accompanies this disease [5,6]. The prevalence of epilepsy reported in patients with CP is between 15% and 55%, and it is critical for the identification of child and family needs in terms of health [7]. Epilepsy has serious effects on the child's health status and the QOL and it also has negative effects on families and parents [7]. The physical and psychosocial burden of the illness on families and mothers as primary caregivers who have to look after their disabled children all day and for many years can negatively affect the QOL [8]. It is also considered that by addressing the problems that will arise, effective solutions can be produced, and parents can have more comprehensive care with their children. This will help set the right rehabilitation goals for these patients. In the treatment of children with CP, the concept of family-based care has become the recent trend, and the positive caregiver role and interest can improve the QOL of the child. Thus, the psychosocial consequences for these children and their families can be more positively affected [5].

In this study, we aim to determine the likely effects of epilepsy in children with CP on the life quality of the mother and family and how psychological, economic, social and cultural situation of the child, the mother and the family will be affected.

Material and Methods

Setting and Participants

This study was conducted between September 2016 and October 2017 at the Private Aktif Medicine Central Physical Therapy and Rehabilitation clinic. The study was initiated following the approval of Istanbul University Cerrahpaşa Faculty of Medicine, Clinical Research Ethics Committee (number: 83045809/604.01/02-280029, date: 04.09.2015).

A prospective study was conducted with three groups (CP with epilepsy, CP without epilepsy, and a healthy control group) of children between the ages of 2 and 18, as well as mothers and a control group of mothers with healthy children. According to the GMFCS, which can express fear or discomfort, non-disabled literate mothers of children of all levels and all types of CP were included in the study. The exclusion criteria in the study were as follows: significant changes in the social, health or economic conditions of the family or of mother during the last three months (which may have changed the perception of QOL); the primary caregiver of a child with CP is someone other than the mother; mother and father are separated; a child with CP does not live with the family; a child with CP or a mother has aggressive or self-harmful behavior; a mother being pregnant, diagnosed with severe psychiatric disorder or chronic systemic disease, or a mother having a disability.

Evaluation and Outcome Measures

The clinical and demographic characteristics (gender, age, age at diagnosis, previous and current treatments (antiepileptic or antispastic medications and botulinum toxin-A injection), history of operations (orthopedic musculoskeletal surgery), and the etiology of CP (premature, intrauterine hypoxia, asphyxia, postnatal hemorrhage, meningitis or the other postnatal factors and idiopathic) of all CP cases were questioned.

Gross motor function classification system (GMFCS) [9], and Manual Ability Classification System (MACS) [10], staging of patients with CP were performed. These measures and classifications are tools that assess the severity of movement disorders in children with CP and allow measurement of their skills and limitations. The GMFCS level sets lower extremity walking functions and the MACS level sets the hand skill levels between I and V.

36-item Short Form Health Survey

The mother's QOL was assessed using the 36-item Short Form Health Survey (SF-36). The SF-36 physical component summary (PCS) and mental component summary (MCS) subscales were calculated. The SF-36 is a short but comprehensive, easily applicable and widely used QOL scale with validity and reliability [11]. Scores between 0 and 100 were obtained on the subscales, and higher scores indicate better QOL.

Beach Center Family Quality of Life

The QOL of the family was assessed by the Beach Center Family Quality of Life (BC-FQOL) scale. The BC-FQOL, which was completed by Mothers was developed in 2006 by the University of Kansas [12]. It is a measurement implemented to determine the QOL of developmentally impaired children with validity and reliability in Turkish [13]. BC-FQOL is the data collection tool consisting of quintile rating type answers of 25 questions; Five sub-domains (Family Interaction (FI), Parenting (P), Emotional Well-being (EW-b), Physical/Material Well-being (P/MW-b), Disability-Related Support (D-RS)). The highest score on the entire BC-FQOL scale is 125 (25x5) and the lowest score is 25 (25x1). High scores on the scale with no negative substance indicate a high level of family life quality perception. The family life quality perception can be calculated according to the total scores from the scale, as well as dividing the total score obtained by the number of items. In this study, the five sub-area scales and the total score were evaluated based on the ratio divided by the number of items (Total ratio = TR). Disability-Related Support (D-RS) was not calculated since the

control group did not have a child with developmental disability and the total ratio (TR) value calculation in this group was determined by dividing the total score by 21.

Statistical Analyses

Basic statistical analyses were performed using the SPSS software (ver. 22.0; SPSS, Inc., Chicago, IL). The normality of the data was assessed using the Shapiro–Wilk test. The statistical analysis of our data was performed using a parametric test (independent samples test and one-way ANOVA). The non-parametric Mann–Whitney U-test was used since the variables were not normally distributed. Categorical variables were evaluated using the Chi- Square test. The post hoc analysis test used in the one-way ANOVA was the Bonferroni test. For all the analyses, P-values of <0.05 were considered statistically significant. The total sample size, effect size (f=0.34), and actual power (0.80) of the study were calculated using the G power statistic program (Heinrich-Heine-University. Dusseldorf, Germany).

Results

Among the 110 individuals evaluated for the study, 85 were mothers of patients with CP, and 25 were mothers with healthy children, which constituted the control group. The study was completed with 86 individuals and analyzed in three groups. There were 39 mothers in the "without epilepsy" group, 22 mothers in the "with epilepsy" group, and 25 mothers in the control group (Figure 1).

The mean age of the patients with CP (mean ± SD) was 7.39 ± 4.16 (years), and the age of diagnosis (mean ± SD) was 15.34 ± 12.45 months. There was no significant difference between the groups (p> 0.05). There were significant differences between the groups in terms of etiology, medication history, CP type, MACS and GMFCS levels (p<0.05). These differences showed changes in the groups of "with" or "without epilepsy". Clinical and demographic characteristics of children with CP are displayed in detail in Table 1.

The mean age of the mothers in the control group, without epilepsy and with epilepsy groups were (mean ± SD) 36.36 ± 6.81, 33.72 ± 6.97, and 36.27 ± 5.68 years, respectively. There was no significant difference between the groups (p> 0.05). The level of education of 53 (61.6%) of the mothers was primary school and 60 (69.7%) of them were housewives (Table 2).

Although the SF-36 PCS and SF-36 MCS scores were highest in the control group and lowest in the epilepsy group, there was no significant difference between the groups (p> 0.05) (Figure 2).

When the BC-FQOL subscales, evaluating the QOL of the families were examined, the Emotional Well-being scores (EW-b) were the lowest in the epilepsy group, and children who had CP with epilepsy had significantly lower emotional competence than the control group (p = 0.001). With regard to the Disability-Related Support (D-RS) scores, the "with epilepsy" group had the lowest score and it was significantly different from families with children who had CP without epilepsy (p = 0.045). In the other BC-FQOL subscales, there was no significant difference between the groups (p> 0.05) (Figure 2).

The families lived in the same neighborhood with low socioeconomic status. Among the factors that could affect the FQOL: the socioeconomic status of the families and the age and profession of the mother possessed similar features between the age and genders of children groups with CP (Table 1, 2).

Table 1. Demographic and clinical characteristics of patients with cerebral palsy

	Total (n=61)	Without Epilepsy (n=39)	With Epilepsy (n=22)	p
Gender*				
Female	25	17	8	0.582
Male	36	22	14	
Age** (years; median, (mean±SD))	6 (7.39±4.16)	5.5 (7.15±4.34)	7.25 (7.81±3.89)	0.306
Age of diagnosis** (months; median, (mean±SD))	12 (15.34±12.45)	12 (16.28±13.33)	12 (13.68±10.80)	0.511
Types of child birth methods*				
Vaginal	32	22	10	0.411
Section	29	17	12	
Etiology*				
Premature	27	19	8	<0.001
Hypoxia/asphyxia	13	8	5	
Postnatal factors	12	4	8	
Idiopathic	9	8	1	
Medication history*				
Antiepileptic	16	0	16	<0.001
Antispastic	3	3	0	
Both of them	6	0	6	
None	36	36	0	
History of Botulinum toxin-A injection*				
Positive	15	10	5	0.800
None	46	29	17	
History of orthopedic surgery*				
Positive	19	12	7	0.147
None	42	27	15	
Type of CP*				
Spastic	53	36	17	<0.001
Hemiplegia	11	8	3	
Diplegia	17	14	3	
Quadriplegia	25	14	11	
Dyskinetic	0	0	0	
Ataxic	3	1	2	
Hypotonic	2	0	2	
Mixed	3	2	1	
GMFCS level*				
I	13	10	3	0.001
II	8	5	3	
III	7	4	3	
IV	17	13	4	
V	16	7	9	
MACS level*				
I	18	15	3	<0.001
II	16	9	7	
III	12	10	2	
IV	9	5	4	
V	6	0	6	

GMFCS: Gross Motor Function Classification System; MACS: Manuel Ability Classification System; *Chi- Square test, **Mann-Whitney U test; * p<0.05

Table 2. Demographic characteristics of mothers of children with cerebral palsy

	Total (n=86)	Control (n=25)	Without Epilepsy (n=39)	With Epilepsy (n=22)	p
Age (years; mean±SD) ++	35.14±6.67	36.36±6.81	33.72±6.97	36.27±5.68	0.199
Level of Education*					
Primary school	53	14	27	12	0.011
Middle school	14	4	7	3	
High school	16	6	5	5	
University	3	1	0	2	
Job*					
Housewife	60	15	28	17	0.221
Part time	14	5	7	2	
Full time	12	5	4	3	

++ One-way ANOVA test; *Chi- Square test

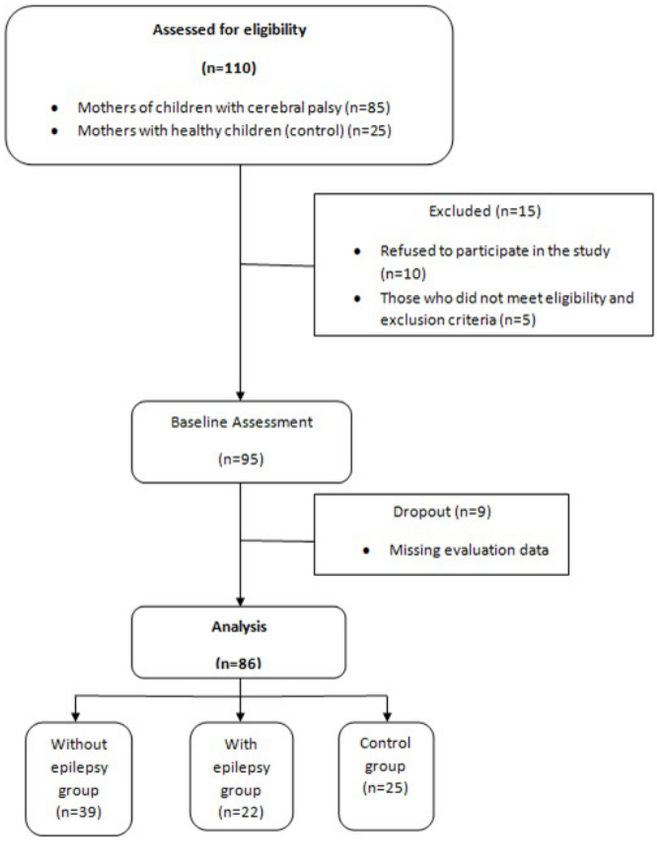
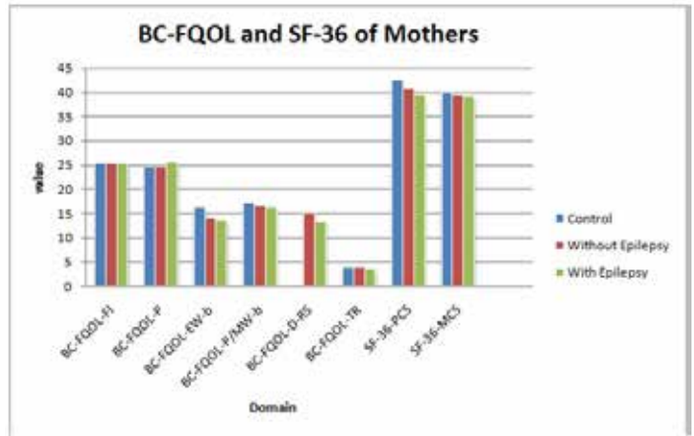


Figure 1. Study flow chart



	Control (mean±SD) (n=25)	Without Epilepsy (mean±SD) (n=39)	With Epilepsy (mean±SD) (n=22)	p value**
BC-FQOL-FI	25.32±3.03	25.28±3.55	25.27±3.96	0.999
BC-FQOL-P	24.72±2.88	24.69±3.55	25.45±3.48	0.664
BC-FQOL-EW-b***	16.28±1.72	14.05±3.17	13.59±2.75	0.001*
BC-FQOL-P/MW-b	17.36±3.32	16.54±3.61	16.27±5.33	0.617
BC-FQOL-D-RS**	nd	15.28±3.06	13.36±4.18	0.045*
BC-FQOL-TR	3.98±0.41	3.83±0.53	3.75±0.51	0.284
SF-36-PCS	42.65±6.59	40.83±8.21	39.31±10.1	0.393
SF-36-MCS	40.1±4.94	39.42±7.68	39.03±8.71	0.876

Figure 2. BC-FQOL and SF-36 components values graphics of mothers of children with CP, with or without epilepsy and control groups. SF-36: 36-item Short-Form Health Survey; PCS: physical component summary; MCS: mental component summary; BC-FQOL: Beach Center Family Quality of Life; FI: Family Interaction; P: Parenting; EW-b: Emotional Well-being; P/MW-b: Physical/Material Well-being; D-RS: Disability-Related Support; TR: Total ratio
++One-way ANOVA test; ***post hoc analysis test Bonferroni p-value: (control-without epilepsy=0.006, control- with epilepsy=0.003); **Independent samples test; *p<0.05

Discussion

The present functional deficits and cognitive problems of children with CP can create an important physical and psychological burden for the family, especially for the caregiver mother [3,4]. This situation has negative effects on the QOL, which is a subjective concept and assesses one's life problems according to their own perceptions [6,14]. This effect can be seen in the QOL of the patient, the mother and the family [2,5]. In the literature, studies investigating the QOL of CP or epileptic children and their mothers and the factors affecting them (such as motor function levels) are frequently encountered [5,14]. In addition, studies examining the family life qualities of this group are also seen, but less frequently [2,15,16]. However, no study has been found in the literature on combined work to evaluate the effects of the presence of epilepsy in children with CP on the QOL of mothers and families. Studies in the literature have reported that childhood epilepsy has serious effects on the QOL and psychological health of parents and that the control of epileptic seizures is associated with an improvement in parental QOL [8]. In a review by Puka et al. it was reported that childhood epilepsy disrupted the QOL of the parents, that the family environment and child/parent health had two-way interactions in epilepsy, and that family interventions should be aimed for the treatment [17]. For this reason, our study is important in terms of examining the interactions of the QOL of mothers and their families with children with both epilepsy and CP.

In another study, after 10 years of follow-up of epileptic children, Puka et al. evaluated their mothers' QOL in the SF-36 mental and physical health sub-headings [18]. It was observed that these mothers had similar mental health subscale scores compared to the normal population, and had better scores on physical health subscale scores. It is argued that a mother who has to look after a physically disabled child throughout the day is more likely to have psychiatric and physical health problems. [19] In a study by Mobarak et al., 41.8% of mothers of children with CP were found to have a risk of psychiatric morbidity [20]. In a study where they evaluated the quality of life of 424 mothers with children with CP, Dehghan et al. determined the PCS and MCS scores of 39.21 and 41.23, respectively [16]. This

indicated that the mothers had low level of QOL. For this reason, QOL has been of particular concern for mothers with children who have CP, and rehabilitation specialists have suggested that strategies should be developed to support the QOL of the mothers. In the recent study, the QOL of mothers was assessed with SF-36 MCS and PCS, and general maternal QOLs were found to be low, similar to the scores in the study conducted by Dehghan et al. There was no significant difference in the QOL between mothers of children with CP without epilepsy and mothers of children with CP with epilepsy [16]. However, it was observed that mothers of children with CP with epilepsy had a worse QOL tendency in both physical and mental health domains. A similar situation was observed in the study by Terra et al., and the low QOL in mothers of children with CP with epilepsy was not significant compared to the group without epilepsy and the control groups [5].

The QOL of a child with a disability is affected by the QOL of the family as well as that of the caregiver [21]. These children bring a burden to the family, both in terms of health and economics [22]. In order to determine the needs of the child with CP, the whole family should be included in the education, treatment planning and implementation processes [23]. Working together with family members on this issue can better meet the needs of children with disabilities [22]. In this respect, the recognition of the characteristics of the family that are important in families with children with disabilities further improved the FQOL concept [14].

Although FQOL data have been studied in many cohorts, the literature specifically examining the effects of CP characteristics on children with FQOL is limited, and the results show differences [14,24].

Magill-Evans et al. reported that families with young adolescents with CP and families with an adolescent without any disabilities had more similarities than differences in terms of QOL [25]. They stated that the child with CP may be a challenge for the parents, but the conclusion of the study emphasized that the existence of a disabled family member may not always reduce the QOL. Dobhal et al. reported that the QOL was severely affected in three-quarters of 100 children with CP and their families [15]. They stated that QOL's physical independence, mobility and social integration dimensions were affected more than the clinical burden, economic burden and schooling dimensions. They also commented on the more significant presence of low QOL in patients with quadriplegic CPs and their families, explaining that comorbidities such as epilepsy were more common in this group [26]. Davis and Gavidia-Payne reported that FQOL satisfaction and disability severity were not associated with children with disabilities, but said that FQOL was positively associated with the family income, caregiver training, family support and good family-centered service [24]. In the recent study, children with epileptic CP generally tended to have a lower FQOL. In this group, emotional well-being and disability related support scores were significantly lower. There was no difference in the FQOL scores of family interaction, parenting, physical/material well-being, and total rate between children with CP with or without epilepsy.

Emotional well-being refers to the presence of individuals and institutions through which individuals can talk and share personal problems and special issues [13]. The observation of a low perception of emotional competence can be attributed to the lack of families with adequate emotional support [13]. In the recent study, this may be due to the fact that if a child with CP also has epilepsy, mothers think that they are not receiving the psychological and emotional support they expect from other family members or social circles, and that they cannot spare time for themselves.

Disability-related support is the support that a disabled individual needs to achieve his/her goals in an environment such as home, school, work-place or therapy center [12]. The low level of disability-related support in the group with epileptic CP shows that mothers consider the presence of epilepsy in their children with CP as the reason why their children are not sufficiently supported to achieve their goals in such environments.

Limitation

Several possible limitations should be considered when interpreting the results of this study. The main limitation is that the number of studies on the subject is small, and clinical populations have similar socio-economic characteristics living in the same region. For this reason, the results may not reflect the findings of mothers of children with CP and their families in the country as a whole, since they only represent the population participating in the study.

Another limitation is that it is not known what the status of the families' living quarters is before the child has CP, because the study is a time-limited cross-sectional study. However, despite all these limitations, the results between the groups were comparable due to the presence of a healthy control group in the study and the similarity in the socio-demographic data of the study population.

Conclusion

CP has a negative impact on the QOL of the child, mother and family. The effects of the presence of epilepsy in CP on the QOL of mothers and their families are not clear. In this study, it was observed that mothers of children with epileptic CP had a worse QOL tendency in both mental and physical health, but there was no significant difference between them and other mothers. The FQOL perception of mothers tended to be lower in families with epileptic CP, and emotional well-being and disability-related support levels were found to be significantly worse than in other families.

As a result, the mother as the primary caregiver and the family as the main support center should indispensably have a good QOL, so that the needs of the CP child, with or without epilepsy, can be fulfilled and treatment is effective and sustainable.

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Scientific Responsibility Statement

The authors declare that they are responsible for the article's scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

Animal and human rights statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with

the 1964 Helsinki declaration and its later amendments or comparable ethical standards. No animal or human studies were carried out by the authors for this article.

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Conflict of interest

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