



Correlates of quality of life in mothers of children with diagnosed epilepsy

Offer E. Edelstein^{a,*}, Talia Shorer^b, Zamir Shorer^c, Yaacov G. Bachner^d

^a Ben-Gurion University of the Negev, The Spitzer Department of Social Work, Beer-Sheva 841050, Israel

^b Soroka Medical Center, Head Nurse Manager, Beer-Sheva 841050, Israel

^c Soroka Medical Center, Pediatric Neurology Unit, Ben-Gurion University of the Negev, 841050, Israel

^d Ben-Gurion University of the Negev, Faculty of Health Sciences, Department of Public Health, Beer-Sheva 8410501, Israel

ARTICLE INFO

Article history:

Received 10 January 2019

Revised 28 January 2019

Accepted 28 January 2019

Available online 1 March 2019

Keywords:

Mothers

Epilepsy

Quality of life

ABSTRACT

Contrary to a plethora of studies on the quality of life (QoL) of parents caring for children with chronic conditions, information regarding parents of children with epilepsy remains limited. The main purpose of the current study was to explore associations between children's biomedical characteristics, mothers' sociodemographic characteristics, mothers' situational factors, and QoL among mothers of children with epilepsy. One hundred and fifty mothers of children with epilepsy completed valid and reliable measures. The study was conducted at a large outpatient clinic for children with epilepsy in a central hospital in southern Israel. Sense of mastery and optimism emerged as significant predictors of all four domains of QoL; self-rated health (SRH) and mothers' socioeconomic status were significant predictors of three QoL domains; mothers' sleeping disturbances and children's behavioral problems predicted one QoL component. These results highlight the pivotal role that mastery and optimism play in securing the QoL of mothers caring for children with epilepsy. Moreover, mother's socioeconomic status and SRH should also be screened to deal with possible socioeconomic deprivation. In addition, health professionals should screen mothers and children for sleeping disturbances, and provide information about sleep hygiene. Psychosocial interventions need to be developed and offered to parents, in an attempt to address the social and behavior problems of children with epilepsy.

© 2019 Elsevier Inc. All rights reserved.

1. Introduction

Epilepsy is the most common childhood neurological condition [1]. It is conceptually defined as a disorder of the brain, characterized by an enduring predisposition to generate epileptic seizures, and the neurobiologic, cognitive, psychological, and social consequences of this condition [2]. In 2014, the International League Against Epilepsy (ILAE) announced a revised diagnostic definition of epilepsy criteria. A diagnosis of epilepsy current includes the occurrence of any of the following conditions: (a) at least two unprovoked (or reflex) seizures occurring more than 24 h apart; (b) one unprovoked (or reflex) seizure and a probability of further seizures, similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; and (c) a diagnosis of an epilepsy syndrome [3].

According to American estimates, from birth to 17 years of age, the prevalence of epilepsy/seizure disorder is 10.2 in 1000 individuals [4]. In Israel, estimates show that the prevalence of epilepsy among the total population reaches 5 in 1000 children [5]. Epilepsy, along with its related seizures, poses a substantial challenge for both children and

parents' mental, functional, and economic status. In addition, epilepsy has deleterious effects on their quality of life (QoL). For example, a recent estimate showed that a family of a child with epilepsy had an additional \$9103.25 in annual expenditures related to medical costs – the highest level of medical expense compared to children with asthma, diabetes, food allergies, and hypertension [6]. Other studies have indicated that epilepsy may have greater deleterious effects on the QoL of children and youth than asthma [7–9] and diabetes [10], or as compared with the QoL of healthy children [11]. Moreover, children with epilepsy may exhibit more mental, behavioral, and scholastic difficulties [4] than children without epilepsy, which places a heavy burden on parents.

The inevitable impact of children's health issues and behavior difficulties on their parents' QoL has been well-acknowledged in numerous studies and in regard to various chronic conditions such as Asperger syndrome [12], cerebral palsy [13], asthma [14,15], chronic renal failure [16], and phenylketonuria (PKU) [17]. Regarding epilepsy, parents need to constantly monitor their children for seizure safety issues and strict medication adherence [18]. They also have to react and adjust to their children's dynamic condition [19]. This situation is usually characterized by high levels of emotional and physical exhaustion [20], and might even reach a level of posttraumatic stress or major depressive disorder [21]. Surprisingly, in contrast to a plethora of studies on the QoL of

* Corresponding author.

E-mail address: offere@bgu.ac.il (O.E. Edelstein).

children and youth with epilepsy, relatively few studies have focused on parental QoL. These studies documented correlations with children's medical variables like seizure control, status epilepticus, drug side effects, and visit status [22]. They also focused on parental mental disorders like anxiety and depression [22]; background factors, such as employment, cost of epilepsy, age, and gender of parents [22]; and socioeconomic state [23].

Recent years have shown a growing interest in the disruption of informal caregivers' sleeping patterns and its ramifications on QoL. Parents of children with complex needs usually experience sleep deprivation, because of the need to stay alert at night. Therefore, these parents might be at a higher risk of poorer health outcomes and reduced daily functioning [24]. In a prior study examining epilepsy, Larson and colleagues [25] found that about 70% of parents felt concerned about night seizures; as regards feeling rested, nearly half reported "rarely" or "never". Other studies indicated that mothers of children with epilepsy had a 7-fold occurrence of sleep disturbances, compared with mothers of children without epilepsy [26]. However, none of these studies used valid tools to assess the impact of sleep disturbances on QoL among parents of children with diagnosed epilepsy.

The literature shows that some epilepsy researches focused on parents' coping resources. For example, Hamama-Raz and Hamama [23] investigated optimism, the tendency to approach life with a positive attitude and the tendency to anticipate favorable outcomes resulting from challenging events [27] as protective factors, which enhance QoL. Although optimism did not emerge as a significant factor in their study, it played a significant role in enhanced QoL among individuals with chronic conditions such as inflammatory bowel diseases (IBD) [28], stroke [29], and in primiparous and multiparous mothers [30]. *Mastery*, the degree to which individuals perceive their ability to control their own life [31], was also found to be a pivotal resource for wellbeing and enhanced mental health in individuals with the human immunodeficiency viruses (HIV) [32], children with neurodevelopmental disabilities [33], and parents of children with cerebral palsy [34]. Lastly, *self-rated health* (SRH) is a profound predictor of caregivers' inflammatory status (even in healthy individuals) [35], burden of care [36], health services utilization [37], mortality [38], and morbidity [39]. To the best of our knowledge, this measure has yet to be investigated as a predictor of QoL in relation to epilepsy.

Promoting a comprehensive understanding about the QoL of parents of children with epilepsy and its associated factors is important, as it might facilitate the development of intervention programs to address these parents' specific needs and challenges. In this study, we sought to explore the existing associations between children's biomedical characteristics, mothers' sociodemographic characteristics, mothers' situational factors, and QoL among mothers of children with epilepsy. We decided to focus on mothers, since they were found to have lower QoL, relative to fathers in various studies [40–42]. Deepening the understanding of the factors associated with QoL among mothers of children with epilepsy could also help develop specific intervention programs for this population.

2. Methods

2.1. Participants

A total of 150 mothers of children with epilepsy participated in the study. Inclusion criteria required that participants (a) be 18 years old and above, (b) have a child with epilepsy diagnosis according to the currently accepted diagnostic criteria by pediatric neurologists, and (c) have the ability to understand and complete the questionnaire. In order to compute the minimal sample size for a final model with 10 predictors, we used Stevens's rule [74] of a 15:1 (subject-to-variable) ratio. We approached 174 potential mothers; 24 were excluded as they failed to complete the interview. The total response rate was 86.2% (150/174).

Mothers and children's sociodemographic and health-related variables are presented in Table 1. The mothers' mean age was about 40 years (standard deviation [S.D.] 7.9); the average number of years of education was 13.8. The vast majority were married, with an average of 3.2 children, held a job, and rated their socioeconomic status as 'fair' to 'good'. Most of them ranked their SRH as 'good', reported mild sleep disturbances, and relatively high levels of mastery and optimism. Most of the mothers reported full to partial control over the children's convulsions. The children's mean age was 10 years (S.D. 5.6); approximately 51% were males. The majority of children were 'middle' children or the youngest; only 20% as reported by the mothers had severe convulsions. Most of them experienced a convulsion once a month or at a lower frequency rate, and were prescribed one to two anticonvulsants. About one-third reported adverse effects, 40% had behavior problems, and about 34% experienced scholastic difficulties.

Table 1
Sociodemographic and health characteristics of mothers and children (n = 150).

| | Mothers | Children |
|--|----------------|--------------|
| Married, % | 85.3 | |
| Single/Divorced/Widow % | 14.7 | |
| Age, Mean (S.D.) | 40.36 (7.9) | 10.00 (5.60) |
| Number of children, Mean (S.D.) | 3.22 (1.5) | |
| Holding a job, % | 98% | |
| Years of education, Mean (S.D.) | 13.80 (2.48) | |
| Socioeconomic status (%): | | |
| Very good | 9.5 | |
| Good | 46.6 | |
| Fair | 41.2 | |
| Bad | 2.0 | |
| Very bad | 0.7 | |
| Mothers' self-rated health status, Mean (S.D.) | 1.92 (.78) | |
| Mothers' sleep disturbances, Mean (S.D.), Median | 6.93 (3.60), 7 | |
| Mothers' sense of mastery, Mean (S.D.) | 2.38 (.82) | |
| Mothers' optimism, Mean (S.D.) | 22.91 (4.86) | |
| Gender of child (%) | | |
| Male | | 51.3 |
| Female | | 48.7 |
| Birth Order (%) | | |
| Eldest | | 34.2 |
| Middle | | 27.5 |
| Youngest | | 38.3 |
| Severity of convulsions (%) | | |
| Severe | | 19.7 |
| Mild | | 40.8 |
| Low | | 39.5 |
| Frequency of convulsions (%) | | |
| Every day | | 15.2 |
| Once a week | | 13.0 |
| Once a month | | 14.5 |
| Every few months | | 57.2 |
| Number of medications (%) | | |
| 1 | | 53.5 |
| 2 | | 27.1 |
| 3 or more | | 19.5 |
| Side effects (%) | | |
| Yes | | 36.1 |
| No | | 63.9 |
| Maternal perceived control over convulsions (%) | | |
| Full control | | 50.3 |
| Partial control | | 30.1 |
| No control | | 19.6 |
| Child behavior problems (%) | | |
| Yes | | 39.6 |
| No | | 60.4 |
| Child scholastic problems (%) | | |
| Yes | | 34.2 |
| No | | 65.8 |

2.2. Measures

2.2.1. Dependent variable

2.2.1.1. Maternal QoL. The QoL was assessed using the WHO Quality of Life-BREF (WHOQOL-BREF) [43]. This questionnaire comprises 26 items, two of which measure overall QoL and general health. The other 24 items are grouped into four domains: physical, psychological, environmental, and social relationships. Each item is scored on a 5-point Likert scale, ranging from 1 “strongly disagree” to 5 “strongly agree”. The scores are then transformed into a linear scale, ranging from 0 to 100, a higher score indicates better QoL. The internal consistency was good to satisfactory (Cronbach's $\alpha = 0.77, 0.74, 0.72,$ and $0.70,$ respectively).

2.2.2. Independent variables

2.2.2.1. Self-rated health. Mothers' SRH was assessed using two items – “In general, how would you assess your health?” and “In general, how would you assess your health compared to other people your age?” – based on a 5-point scale, ranging from 1 “Excellent” to 5 “Extremely poor”. The correlation between the two items was $r = 0.82$. An overall score for this scale was obtained by averaging the answers to both items, a higher score indicating worse SRH.

Optimism was assessed using the Life Orientation Test (LOT) [44]. This tool comprises 12 items out of which 4 items assess the construct of optimism (e.g., “In uncertain times, I usually expect the best”), and 4 items evaluate the construct of pessimism (e.g., “I hardly ever expect things to go my way”). The 4 remaining items are referred to as ‘filler items’ and are not part of the sum scores. Items are scored on a 5-point Likert scale, ranging from 0 “very much disagree” to 4 “very much agree”. The ‘pessimism’ items are reverse scored. A total scale sum score was computed and ranges between 0 and 32. Higher scores indicate a higher sense of optimism. The internal consistency was satisfactory (Cronbach's $\alpha = 0.70$).

Sense of mastery was measured by the Pearlin–Schooler Mastery Scale [45]. The scale is composed of 7 items that measure the extent to which one's life is considered to be under one's own control (e.g., “I can do almost everything I decide to do”; and “Sometimes I feel hopeless about coping with my problems in life”). Responses were given on a 5-point scale, ranging from 1 “totally disagree” to 5 “totally agree”. The total score is the average of the responses to all items. A high score indicates a strong sense of mastery. The internal consistency was good (Cronbach's $\alpha = 0.78$).

Sleep disturbances were measured using the Pittsburgh Sleep Quality Index (PSQI) [46]. This index consists of 19 items, tapping seven domains of sleep difficulties: subjective sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbances, use of sleep medication, and daytime dysfunction. Each domain is scored on a scale of 0–3. A global score of overall sleep quality was calculated by summing the domains' scores, ranging from 0 to 21. Global scores of >5 indicate poor sleep. The internal consistency was satisfactory (Cronbach's $\alpha = 0.71$).

2.2.2.2. Mothers' sociodemographic characteristics. These included information about family status (married/other), age (in years), number of children, employment status (yes/no), and education (in years).

Economic status was assessed using the following item: “How would you define your economic status?”, with possible answers ranging from 1 “Very good” to 5 “Extremely poor”.

2.2.2.3. Children's sociodemographic and health characteristics. These included information regarding age (in years), gender (male/female), education (in years), position in the family (eldest, middle, youngest), convulsion severity (severe, mild, low), frequency of convulsions (every day, once a week, once a month, once every few months),

number of prescribed anticonvulsants, medication adverse effect (yes/no), perceived control over convulsions (full/partial/no), behavior problems (yes/no), and scholastic problems (yes/no).

2.3. Procedure

Complying with the inclusion criteria, pediatric neurologists identified suitable potential participants and provided them with an explanation about the study and its importance. Mothers who were interested in participating signed an informed consent form and completed the questionnaires. The study protocol was approved by the Helsinki Committee of Soroka University Medical Center. The data obtained from the questionnaires were coded anonymously to an encrypted file stored in the university computers.

2.4. Statistical analysis

We used descriptive statistics (percentages, means, and S.D.) to describe the sample and study variables. According to scale structures, Pearson's or Spearman's correlation coefficients were computed to assess the associations between QoL and research variables. Differences among mean values of continuous variables were tested using *t*-test and analysis of variance (ANOVA). For each of the four QoL domains, a multiple linear regression model was calculated. Only variables that correlated significantly with QoL in bivariate analyses were included as independent variables in these analyses. Internal reliability of scales was assessed using Cronbach's alpha coefficient. The data were analyzed with the statistical software SPSS, PC version 26.0. Significance level was set at $p < 0.05$.

3. Results

As shown in Table 2, participants reported an average of 68 points on all QoL domains. The regression models for the four domains of QoL included seven independent variables: convulsion control, child's behavior problem, mother's SRH, mother's sleep disturbances, mother's socioeconomic status, sense of mastery, and optimism. Several statistically significant associations were found between the study variables and four QoL domains (Table 3). Regarding the mothers' characteristics, higher socioeconomic status, better SRH, less sleep disturbances, higher endorsement of optimism, and mastery were associated with higher scores for all four QoL domains (i.e., enhanced QoL). Mothers' education level was only positively associated with the physical component of QoL. Two situational variables emerged as significant regarding their association with QoL. Mothers who reported no control over their child's convulsions tended to report lower scores on the environmental and social domains of QoL. Mothers who reported higher levels of behavior problems tended to report lower scores for the social and physical domains of QoL. No other statistically significant associations were found between QoL domains and any other study variables.

A correlation matrix of all the independent variables that were found to be significantly associated with QoL domains was examined. The associations among the different variables were low to moderate, in a range between $0.11 < r < 0.49$ (mother's education and sleep disturbances; optimism and sense of mastery, respectively) in absolute value. In medical research, the acceptable boundary for multicollinearity is $r > 0.70$ [47].

Table 2
Descriptive statistics of QoL components (n = 150).

| Variables | No. of items | Possible range | Mean | SD |
|-------------------------|--------------|----------------|-------|-------|
| Physical component | 7 | 0–100 | 68.41 | 16.12 |
| Psychological component | 6 | 0–100 | 68.30 | 16.14 |
| Environmental component | 8 | 0–100 | 68.74 | 13.02 |
| Social component | 3 | 0–100 | 68.25 | 20.11 |

Table 3
Correlates of study variables with QoL components (n = 150).

| Variables | No. of items | Range | Mean (SD) | Physical component | Psychological component | Environmental component | Social component |
|--|--------------|-------|--------------|--------------------|-------------------------|-------------------------|------------------|
| Mothers' age, Mean (S.D.) | 1 | 23–62 | 40.36 (7.94) | r = 0.07 | r = 0.06 | r = 0.02 | r = -0.09 |
| Number of children, Mean (S.D.) | 1 | 1–11 | 3.22 (1.55) | r = -0.03 | r = 0.04 | r = -0.09 | r = -0.13 |
| Mothers' years of education, Mean (S.D.) | 1 | 10–22 | 13.80 (2.50) | r = 0.17* | r = 0.12 | r = 0.135 | r = 0.05 |
| Socio-economic status | 1 | 1–5 | 2.38 (0.72) | r = -0.22** | r = -0.34*** | r = -0.44*** | r = -0.36** |
| Self-rated health status, Mean (S.D.) | 2 | 1–5 | 1.92 (0.78) | r = -0.61*** | r = -0.36*** | r = -0.42*** | r = -0.22** |
| Mothers' sleep disturbances, Mean (S.D.), Median | 7 | 0–21 | 6.93 (3.60) | r = -0.55*** | r = -0.38*** | r = -0.40*** | r = -0.24** |
| Mothers' sense of mastery, Mean (S.D.) | 7 | 1–5 | 2.38 (0.82) | r = -0.49*** | r = -0.59*** | r = -0.53*** | r = -0.39*** |
| Mothers' optimism, Mean (S.D.) | 8 | 0–32 | 22.91 (4.86) | r = 0.40*** | r = 0.60*** | r = 0.50*** | r = 0.43*** |
| Age of child, Mean (S.D.) | 1 | 0–25 | 10.01 (5.56) | r = 0.03 | r = 0.01 | r = 0.08 | r = 0.02 |
| Gender of child | 1 | | | t = -1.29 | t = -1.22 | t = -1.97 | t = -1.13 |
| Male | | | | 70.17 | 69.95 | 70.92 | 70.19 |
| Female | | | | 66.75 | 66.72 | 66.69 | 66.44 |
| Birth Order | 1 | | | F = 0.78 | F = 0.15 | F = 0.54 | F = 2.43 |
| Eldest | | | | 70.53 | 67.85 | 70.38 | 72.27 |
| Middle | | | | 66.23 | 67.78 | 67.71 | 62.92 |
| Youngest | | | | 68.22 | 69.32 | 68.30 | 68.56 |
| Severity of convulsions | 1 | | | F = 1.24 | F = 0.91 | F = 1.91 | F = 1.31 |
| Severe | | | | 70.92 | 70.41 | 70.75 | 71.30 |
| Mild | | | | 65.70 | 66.03 | 66.16 | 64.86 |
| Low | | | | 69.16 | 69.15 | 70.25 | 69.74 |
| Frequency of convulsions | 1 | | | F = 0.63 | F = 0.09 | F = 0.30 | F = 1.07 |
| Every day | | | | 68.50 | 67.26 | 68.28 | 75.00 |
| Once a week | | | | 64.49 | 67.36 | 67.01 | 65.68 |
| Once a month | | | | 65.17 | 67.21 | 66.38 | 67.08 |
| Every few months | | | | 69.19 | 68.81 | 69.18 | 66.23 |
| Number of medications | 1 | | | F = 0.45 | F = 0.40 | F = 0.09 | F = 0.99 |
| 1 | | | | 68.60 | 68.30 | 69.94 | 65.81 |
| 2 | | | | 69.20 | 68.78 | 68.50 | 68.91 |
| 3 or more | | | | 65.74 | 66.31 | 67.70 | 71.66 |
| Control over convulsions | 1 | | | F = 0.85 | F = 1.41 | F = 3.24* | F = 2.90* |
| Full control | | | | 69.03 | 70.37 | 69.87 | 68.66 |
| Partial control | | | | 68.57 | 66.47 | 70.20 | 71.12 |
| No control | | | | 64.44 | 65.00 | 63.00 | 59.61 |
| Child's behavior problems | 1 | | | t = -2.72** | t = -1.79 | t = -1.82 | t = -2.77** |
| Yes | | | | 63.78 | 65.21 | 66.22 | 62.35 |
| No | | | | 70.99 | 70.02 | 70.20 | 71.57 |
| Child's scholastic problems | 1 | | | t = -0.45 | t = -0.66 | t = -1.12 | t = -1.16 |
| Yes | | | | 67.35 | 66.91 | 66.93 | 65.27 |
| No | | | | 68.62 | 68.77 | 69.52 | 69.38 |

* p < 0.05.
** p < 0.01.
*** p < 0.001.

Results of the multivariate linear regression analysis for the four domains of mothers' QoL are presented in Table 4. Only variables that were

significantly associated with QoL in the bivariate analyses were included in the regression analyses. *Sense of optimism* emerged as a significant

Table 4
Multivariate linear regression on QoL components (n = 150).

| Variables | Physical component of QoL | Psychological component of QoL | Environmental component of QoL | Social component of QoL |
|-----------------------------------|---------------------------|--------------------------------|--------------------------------|-------------------------|
| Convulsion control β (B) | 0.02 (0.55) | 0.03 (0.58) | 0.01 (0.23) | 0.02 (0.49) |
| Child's behavior problems β (B) | 0.09 (2.96) | 0.07 (2.56) | 0.08 (2.14) | 0.15 (5.98)* |
| Mothers' self-rated health β (B) | -0.42 (-8.62)*** | -0.14 (-2.87)* | -0.18 (-3.03)** | -0.02 (-0.61) |
| Mothers' sleep disturbances β (B) | -0.30 (-1.33)*** | -0.11 (-0.51) | -0.09 (-0.34) | 0.02 (0.14) |
| Mothers' economic status β (B) | 0.06 (1.43) | -0.13 (-3.05)* | -0.24 (-4.38)*** | -0.25 (-6.89)*** |
| Sense of mastery β (B) | -0.25 (-4.89)*** | -0.28 (-5.83)*** | -0.25 (-4.10)*** | -0.17 (-4.21)* |
| Optimism β (B) | 0.15(0.54)* | 0.35 (1.26)*** | 0.27(.76)*** | 0.32 (1.41)*** |
| Adjusted R ² | 0.607 | 0.515 | 0.485 | 0.312 |
| F (df) | 30.60 (7,127)*** | 21.30 (7,127)*** | 18.99 (7,127)*** | 9.70 (7,127)*** |

* p < 0.05.
** p < 0.01.
*** p < 0.001.

predictor of all QoL domains: physical ($\beta = 0.15$, $p < 0.05$), psychological ($\beta = 0.35$, $p < 0.001$), environmental ($\beta = 0.27$, $p < 0.001$), and social ($\beta = 0.32$, $p < 0.001$). Similarly, *sense of mastery* emerged as a significant predictor of all QoL domains: physical ($\beta = -0.25$, $p < 0.001$), psychological ($\beta = -0.28$, $p < 0.001$), environmental ($\beta = -0.25$, $p < 0.001$), and social ($\beta = -0.17$, $p < 0.05$).

Self-rated health emerged as a significant predictor of three QoL domains: physical ($\beta = -0.42$, $p < 0.001$), psychological ($\beta = -0.14$, $p < 0.05$), and environmental ($\beta = -0.18$, $p < 0.01$). *Mother's socioeconomic status* also emerged as a significant predictor of three QoL domains: psychological ($\beta = -0.13$, $p < 0.05$), environmental ($\beta = -0.24$, $p < 0.001$), and social ($\beta = -0.25$, $p < 0.001$). *Sleeping disturbances* emerged as a significant predictor of the physical component of QoL ($\beta = -0.30$, $p < 0.001$), whereas *child's behavioral problems* emerged as a significant predictor of the social component ($\beta = 0.15$, $p < 0.05$). The regression models varied considerably in their explanation percentage of the observed variance of QoL domains. The regression model for the physical component was the highest, followed by the psychological, environmental, and social domains (60.7%, 51.5%, 48.5%, and 31.2%, respectively).

4. Discussion

In contrast to the plethora of studies on the QoL of children and youth with epilepsy, knowledge about their parents' QoL remains scarce. In this study, we sought to explore associations between children's biomedical characteristics, parents' sociodemographic characteristics, situational factors, and QoL among parents of children with epilepsy.

Some significant associations were found between mothers' characteristics, care situation characteristics, and QoL. Two variables emerged as significant predictors of all QoL domains: optimism and mastery. Our findings suggest that parents who reported a stronger tendency to approach life from a positive perspective – even when confronting challenging events (i.e., optimism) [27], as well as control over forces that significantly affect their lives (mastery) [48] – enjoy better QoL. These findings are consistent with many studies emphasizing the major role optimism plays in QoL among the general population [49], as well as in the lives of individuals who face the stressful challenges of chronic conditions, such as, breast cancer [50], autism and Asperger's syndrome [51], and epilepsy [52]. Our findings are also consistent with studies that demonstrated the pivotal role mastery plays when it comes to health outcomes among parents of children with an array of various conditions. For example, *sense of mastery* was a significant predictor of poor physical health among parents of children with developmental disabilities [53], with QoL among mothers of children with diagnosed cancer [54], and among families who face the challenges of hemophilia management [55]. Parents of children with epilepsy have to react and adjust to their children's dynamic condition [19]. Hobfoll and Lilly [27] described *optimism* as individuals' tendency to approach life with a positive perspective, even when confronting challenging events. In this instance, our finding is encouraging as dispositional optimism was found to be positively associated with adaptive coping strategies aiming to eliminate, reduce, or manage stressors or emotions; and negatively associated with less adaptive avoidance coping strategies that attempt to ignore, avoid, or withdraw from stressors or emotion [56]. As for mastery, studies among parents of children with chronic conditions [57] supported the benefits of interventions directed toward boosting mastery, promoting better coping, and enhancing QoL.

With regard to sleep disturbances, according to the literature, a 5 + cutoff score on the total PSQI is considered an indicator of poor sleep quality [58]. The current sample demonstrated an average of 6.93 points (a median of 7 points), suggesting poor sleep quality. In a prior study, Larson and colleagues [25] demonstrated the severe impact of a child with epilepsy on parents' sleep patterns. In our study, *mothers' sleep disturbances* emerged as a significant predictor of the physical domain of

QoL; this factor was also inversely correlated with all of the other domains. Our findings reinforce the findings of prior studies about the association between sleep disturbances, adverse health outcomes, and the diminished daily functioning of parents caring for children with complex needs at home [24]. In addition, caring for such children is known to be associated with maternal mood, stress, and fatigue [59]. Our findings emphasize the need to address sleep disturbances from a holistic familial perspective. Health professionals should screen both parents and children for sleeping disturbances and provide parents with information about sleep hygiene. There is evidence showing that sleep hygiene interventions might improve sleep in children and adolescents [60]. Furthermore, in recent years, there has been a growing research effort to develop automated seizure detection systems. With the understanding that parents need to sleep well and still monitor their children at night, using these devices might be in their best interest. It should be noted that a recent literature review [61] concluded that there are only limited data on which sensor is the most appropriate for each seizure type. Therefore, it is likely that multimodal patient-specific detection systems will be needed in order to meet the complex requirements of seizure detection.

Self-rated health emerged as a significant predictor of physical, psychological, and environmental QoL domains. This finding is consistent with previous studies, which found that patients' SRH provides health professionals with valuable clinical information regarding inflammatory status (even in healthy individuals) [35], burden of care [36], health services utilization [37], mortality [38], and morbidity [39]. There is no doubt that parenting children with epilepsy poses great challenges [19,20]. Given the evidence that improved SRH is associated with both social and physical lifestyles [62], and that productive social activities can favorably moderate the relationship between caregiver burden and self-rated health [63], health professional should encourage parents to maintain physically and socially active lifestyles, as a way to maintain their SRH. This, in turn, might ultimately assist in maintaining or improving their QoL. To the best of our knowledge, the current study is the first to incorporate the SRH measure in caregivers of children with epilepsy. Our findings stress the importance of assessing SRH when treating high-risk groups (i.e., parents of children with chronic conditions). Future studies among caregivers of children with epilepsy are encouraged to incorporate the SRH measure in their studies.

Mother's socioeconomic status emerged as a significant predictor of psychological, environmental, and social domains of QoL. This finding is consistent with findings of a study on mothers of children with Down syndrome, cerebral palsy, and autism spectrum disorder (ASD) [64]. It bears a worrisome implication of socioeconomic deprivation. Shattuck and Parish [65] showed that raising children with disabilities is expensive. The literature documented two patterns concerning mothers of children with disabilities. In the first pattern, the unrelenting demands of care lead to reductions in the working hours of employed parents [66]. In the second (and opposite) pattern, because of their great financial needs, parents of children with disabilities might not have the option of reducing their employment to care for a child with disabilities [67]. In order to reduce socioeconomic deprivation, social workers and health professionals should evaluate the level of unmet needs and plan intervention programs tailored to the unique needs of both parents and children.

Child's behavior problems emerged as a significant predictor of the social component of QoL. Our finding provides further support for the impact that children's behavioral problems have on the family's QoL [42]. Prior studies showed that children with epilepsy were more likely to exhibit behavioral problems [68], social problems, and conduct disorders [4], compared with healthy children. Behavioral problems and unpredictable misbehavior in public evoke parents' embarrassment, which might lead to limited participation in social activities and the avoidance of friends and relatives [69]. The literature documents well the role of social support and social interactions as protective factors for adaptive coping with stress [70] and mood [71] among parents of children with

epilepsy, and QoL among parents of children with chronic conditions such as autism [72], phenylketonuria [17], and pediatric food allergy [73]. Social workers and other health professionals should encourage these parents to consider psychosocial interventions to address their children's social or behavior problems.

Several limitations of our study should be noted. First, we recruited the participants from a single outpatient hospital clinic; thus, the results are not generalizable to other settings. Second, we used a cross-sectional design with a modest sample size; therefore, no causal associations are assumed, and the results should be interpreted with caution. Despite these limitations, our study provides health professionals with a wider understanding about the factors that should be assessed in order to promote better parental QoL. We demonstrated the crucial roles of optimism and sense of control, as protective factors for enhanced parental QoL. We also highlighted the deleterious effects that parents' sleeping problems and children's behavior problems have on parents' QoL.

Our study has practical implications. Designated psychosocial interventions for the health professions should be developed for mothers of children with epilepsy to address their children's social and behavior problems and their own QoL. These programs need to focus on elevating mother's sense of control and optimism and consider using monitoring devices at night in order to enable a better night sleep. All of these might ultimately contribute to enhanced QoL.

Conflicts of Interest

Authors have no conflicts of interest to report.

References

- [1] Jones JE, Austin JK, Caplan R, Dunn D, Plioplys S, Salpekar JA. Psychiatric disorders in children and adolescents who have epilepsy. *Pediatr Rev* 2008;29(2):e9–14.
- [2] Fisher RS, Boas WV, Blume W, Elger C, Genton P, Lee P, et al. Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia* 2005;46:470–2.
- [3] Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, et al. ILAE official report: a practical clinical definition of epilepsy. *Epilepsia* 2014;55(4):475–82.
- [4] Russ SA, Larson K, Halfon N. A national profile of childhood epilepsy and seizure disorder. *Pediatrics* 2012;129(2):256–64.
- [5] Cohen R, Senecky Y, Shuper A, Inbar D, Chodick G, Shalev V, et al. Prevalence of epilepsy and attention-deficit hyperactivity (ADHD) disorder: a population-based study. *J Child Neurol* 2013;28(1):120–3.
- [6] Miller GF, Coffield E, Leroy Z, Wallin R. Prevalence and costs of five chronic conditions in children. *J Sch Nurs* 2016;32(5):357–64.
- [7] Austin JK, Smith MS, Risinger MW, McNelis AM. Childhood epilepsy and asthma: comparison of quality of life. *Epilepsia* 1994;35(3):608–15.
- [8] Austin JK, Huster GA, Dunn DW, Risinger MW. Adolescents with active or inactive epilepsy or asthma: a comparison of quality of life. *Epilepsia* 1996;37(12):1228–38.
- [9] Wang J, Wang Y, Wang LB, Xu H, Zhang XL. A comparison of quality of life in adolescents with epilepsy or asthma using the Short-Form Health Survey (SF-36). *Epilepsy Res* 2012;101(1):157–65.
- [10] Beattie PE, Lewis-Jones MS. A comparative study of impairment of quality of life in children with skin disease and children with other chronic childhood diseases. *Br J Dermatol* 2006;155(1):145–51.
- [11] Miller V, Palermo TM, Grewe SD. Quality of life in pediatric epilepsy: demographic and disease-related predictors and comparison with healthy controls. *Epilepsy Behav* 2003;4(1):36–42.
- [12] Allik H, Larsson JO, Smedje H. Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. *Health Qual Life Outcomes* 2006;4(1):1.
- [13] Davis E, Shelly A, Waters E, Boyd R, Cook K, Davern M. The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child Care Health Dev* 2010;36(1):63–73.
- [14] Cerdan NS, Alpert PT, Moonie S, Cyrkiel D, Rue S. Asthma severity in children and the quality of life of their parents. *Appl Nurs Res* 2012;25(3):131–7.
- [15] Crespo C, Carona C, Silva N, Canavarro MC, Dattilio F. Understanding the quality of life for parents and their children who have asthma: family resources and challenges. *Contemp Fam Ther* 2011;33(2):179–96.
- [16] Wiedebusch S, Konrad M, Foppe H, Reichwald-Klugger E, Schaefer F, Schreiber V, et al. Health-related quality of life, psychosocial strains, and coping in parents of children with chronic renal failure. *Pediatr Nephrol* 2010;25(8):1477–85.
- [17] Fidika A, Salewski C, Goldbeck L. Quality of life among parents of children with phenylketonuria (PKU). *Health Qual Life Outcomes* 2013;11(1):54.
- [18] Elliott JM, Lach L, Smith ML. I just want to be normal: a qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. *Epilepsy Behav* 2005;7(4):664–78.
- [19] Rodenburg R, Meijer AM, Deković M, Aldenkamp AP. Parents of children with enduring epilepsy: predictors of parenting stress and parenting. *Epilepsy Behav* 2007;11(2):197–207.
- [20] Mu PF. Transition experience of parents caring of children with epilepsy: a phenomenological study. *Int J Nurs Stud* 2008;45(4):543–51.
- [21] Iseri PK, Ozten E, Aker AT. Posttraumatic stress disorder and major depressive disorder is common in parents of children with epilepsy. *Epilepsy Behav* 2006;8(1):250–5.
- [22] Lv R, Wu L, Jin L, Lu Q, Wang M, Qu Y, et al. Depression, anxiety and quality of life in parents of children with epilepsy. *Acta Neurol Scand* 2009;120(5):335–41.
- [23] Hamama-Raz Y, Hamama L. Quality of life among parents of children with epilepsy: a preliminary research study. *Epilepsy Behav* 2015;45:271–6.
- [24] McCann D, Bull R, Winzenberg T. Sleep deprivation in parents caring for children with complex needs at home: a mixed methods systematic review. *J Fam Nurs* 2015;21(1):86–118.
- [25] Larson AM, Ryther RC, Jennesson M, Geoffrey AL, Bruno PL, Anagnos CJ, et al. Impact of pediatric epilepsy on sleep patterns and behaviors in children and parents. *Epilepsia* 2012;53(7):1162–9.
- [26] Shaki D, Goldbart A, Daniel S, Fraser D, Shorer Z. Pediatric epilepsy and parental sleep quality. *J Clin Sleep Med* 2011;7(5):502–6.
- [27] Hobfoll SE, Lilly RS. Resource conservation as a strategy for community psychology. *J Community Psychol* 1993;21(2):128–48.
- [28] Cohen I, Benyamini Y, Tulchinsky H, Dotan I. The associations of optimism, social support, and coping strategies with health-related quality of life in a cohort of patients after proctocolectomy with ileal Pouch-anal anastomosis. *J Crohns Colitis* 2017;11(suppl_1):S183.
- [29] Hoefman R, Payakachat N, van Exel J, Kuhlthau K, Kovacs E, Pyne J, et al. Caring for a child with autism spectrum disorder and parents' quality of life: application of the CarerQoL. *J Autism Dev Disord* 2014;44(8):1933–45.
- [30] Loh J, Harms C, Harman B. Effects of parental stress, optimism, and health-promoting behaviors on the quality of life of primiparous and multiparous mothers. *Nurs Res* 2017;66(30):231–9.
- [31] Skaff MM, Pearlín LI, Mullan JT. Transitions in the caregiving career: effects on sense of mastery. *Psychol Aging* 1996;11(2):247.
- [32] Gibson K, Rueda S, Rourke SB, Bekele T, Gardner S, Fenta H, et al. Mastery and coping moderate the negative effect of acute and chronic stressors on mental health-related quality of life in HIV. *AIDS Patient Care STDS* 2011;25(6):371–81.
- [33] Dahan-Oliel N, Shikako-Thomas K, Majnemer A. Quality of life and leisure participation in children with neurodevelopmental disabilities: a thematic analysis of the literature. *Qual Life Res* 2012;21(3):427–39.
- [34] Ketelaar M, Volman MJM, Gorter JW, Vermeer A. Stress in parents of children with cerebral palsy: what sources of stress are we talking about? *Child Care Health Dev* 2008;34(6):825–9.
- [35] Christian LM, Glaser R, Porter K, Malarkey WB, Beversdorf D, Kiecolt-Glaser JK. Poorer self-rated health is associated with elevated inflammatory markers among older adults. *Psychoneuroendocrinology* 2011;36(10):1495–504.
- [36] Abdollahpour I, Nedjat S, Noroozian M, Salimi Y, Majdzadeh R. Caregiver burden: the strongest predictor of self-rated health in caregivers of patients with dementia. *J Geriatr Psychiatry Neurol* 2014;27(3):172–80.
- [37] DeSalvo KB, Jones TM, Peabody J, McDonald J, Fihn S, Fan V, et al. Health care expenditure prediction with a single item, self-rated health measure. *Med Care* 2009;47(4):440–7.
- [38] Tamayo-Fonseca N, Quesada JA, Nolasco A, Melchor I, Moncho J, Pereyra-Zamora P, et al. Self-rated health and mortality: a follow-up study of a Spanish population. *Public Health* 2013;127(12):1097–104.
- [39] Latham K, Peek CW. Self-rated health and morbidity onset among late midlife US adults. *J Gerontol Ser B Psychol Sci Soc Sci* 2012;68(1):107–16.
- [40] Mendes TP, Crespo CA, Austin JK. Family cohesion, stigma, and quality of life in dyads of children with epilepsy and their parents. *J Pediatr Psychol* 2017;42(6):689–99.
- [41] Reilly C, Taft C, Nelander M, Malmgren K, Olsson I. Health-related quality of life and emotional well-being in parents of children with epilepsy referred for presurgical evaluation in Sweden. *Epilepsy Behav* 2015;53:10–4.
- [42] Soria C, Callu D, Viguier D, El Sabbagh S, Bulteau C, Laroussin F, et al. Parental report of cognitive difficulties, quality of life and rehabilitation in children with epilepsy or treated for brain tumour. *Dev Neurorehabil* 2008;11(4):268–75.
- [43] WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med* 1998;28(3):551–8.
- [44] Scheier MF, Carver CS. Optimism, coping, and health: assessment and implications of generalized outcome expectancies. *Health Psychol* 1985;4(3):219–47.
- [45] Pearlín LI, Schooler C. The structure of coping. *J Health Soc Behav* 1978;19(3):2–21.
- [46] Buysse DJ, Reynolds III CF, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh sleep quality index: a new instrument for psychiatric practice and research. *Psychiatry Res* 1989;28(2):193–213.
- [47] Yoo W, Mayberry R, Bae S, Singh K, He Q, Lillard Jr JAW. Study of effects of multicollinearity in the multivariable analysis. *Int J Appl Sci Technol* 2014;4(5):9–19.
- [48] Pearlín LI, Menaghan EG, Lieberman MA, Mullan JT. The stress process. *J Health Soc Behav* 1981;22(4):337–56.
- [49] Schou-Bredal I, Heir T, Skogstad L, Bonsaksen T, Lerdal A, Grimholt T, et al. Population-based norms of the life orientation test-revised (LOT-R). *Int J Clin Health Psychol* 2017;17(3):216–24.

- [50] Finck C, Barradas S, Zenger M, Hinz A. Quality of life in breast cancer patients: associations with optimism and social support. *Int J Clin Health Psychol* 2018;18(1):27–34.
- [51] Cappe E, Wolff M, Bobet R, Adrien JL. Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. *Qual Life Res* 2011;20(8):1279–94.
- [52] Pais-Ribeiro J, da Silva AM, Meneses RF, Falco C. Relationship between optimism, disease variables, and health perception and quality of life in individuals with epilepsy. *Epilepsy Behav* 2007;11(1):33–8.
- [53] Cantwell J, Muldoon OT, Gallagher S. Social support and mastery influence the association between stress and poor physical health in parents caring for children with developmental disabilities. *Res Dev Disabil* 2014;35(9):2215–23.
- [54] Ben-Zur H, Khoury SM. Ethnicity moderates the effects of resources on adjustment of Jewish and Arab mothers of children diagnosed with cancer. *J Psychosoc Oncol* 2017;35(6):688–705.
- [55] Beeton K, Neal D, Watson T, Lee CA. Parents of children with haemophilia—a transforming experience. *Haemophilia* 2007;13(5):570–9.
- [56] Nes LS, Segerstrom SC. Dispositional optimism and coping: a meta-analytic review. *Pers Soc Psychol Rev* 2006;10(3):235–51.
- [57] Grey M, Jaser SS, Whittemore R, Jeon S, Lindemann E. Coping skills training for parents of children with type 1 diabetes: 12-month outcomes. *Nurs Res* 2011;60(3):173–81.
- [58] Gomes AA, Marques DR, Meivavia AM, Cunha F, Clemente V. Psychometric properties and accuracy of the European Portuguese version of the Pittsburgh Sleep Quality Index in clinical and non-clinical samples. *Sleep Biol Rhythms* 2018;16:413–22.
- [59] Meltzer LJ, Mindell JA. Relationship between child sleep disturbances and maternal sleep, mood, and parenting stress: a pilot study. *J Fam Psychol* 2007;21(1):67–73.
- [60] Tan E, Healey D, Gray AR, Galland BC. Sleep hygiene intervention for youth aged 10 to 18 years with problematic sleep: a before-after pilot study. *BMC Pediatr* 2012;12(1):189.
- [61] Ulate-Campos A, Coughlin F, Gainza-Lein M, Fernández IS, Pearl PL, Loddenkemper T. Automated seizure detection systems and their effectiveness for each type of seizure. *Seizure* 2016;40:88–101.
- [62] Benyamini Y. Why does self-rated health predict mortality? An update on current knowledge and a research agenda for psychologists. *Psychol Health* 2011;26:1407–13.
- [63] Yatsugi S, Suzukamo Y, Izumi S. Social activities in mothers of intellectually disabled children moderate the relationship between caregiver burden and self-rated health. *Nihon Koshu Eisei Zasshi* 2013;60(7):387–95.
- [64] Tekinarslan IC. A comparison study of depression and quality of life in Turkish mothers of children with Down syndrome, cerebral palsy, and autism spectrum disorder. *Psychol Rep* 2013;112(1):266–87.
- [65] Shattuck PT, Parish SL. Financial burden in families of children with special health care needs: variability among states. *Pediatrics* 2008;122(1):13–8.
- [66] Crnic KA, Neece CL, McIntyre LL, Blacher J, Baker BL. Intellectual disability and developmental risk: promoting intervention to improve child and family well-being. *Child Dev* 2017;88(2):436–45.
- [67] Parish SL, Cloud JM. Financial well-being of young children with disabilities and their families. *Soc Work* 2006;51(3):223–32.
- [68] Alfstad KA, Clench-Aas J, Van Roy B, Mowinckel P, Gjerstad L, Lossius MI. Psychiatric symptoms in Norwegian children with epilepsy aged 8–13 years: effects of age and gender? *Epilepsia* 2011;52(7):1231–8.
- [69] Leung CYS, Li-Tsang CWP. Quality of life of parents who have children with disabilities. *Hong Kong J Occup Ther* 2003;13(1):19–24.
- [70] Wojtas K, Oskedra I, Cepuch G, Świdarska E. The level of negative emotions, coping with stress and social support for parents of children suffering from epilepsy. *Folia Med Cracov* 2014;54:79–86.
- [71] Ferro MA, Avison WR, Campbell MK, Speechley KN. The impact of maternal depressive symptoms on health-related quality of life in children with epilepsy: a prospective study of family environment as mediators and moderators. *Epilepsia* 2011;52(2):316–25.
- [72] Marsack CN, Samuel PS. Mediating effects of social support on quality of life for parents of adults with autism. *J Autism Dev Disord* 2017;47(8):2378–89.
- [73] Williams NA, Hankey M. Support and negativity in interpersonal relationships impact caregivers' quality of life in pediatric food allergy. *Qual Life Res* 2015;24(6):1369–78.
- [74] Stevens JP. *Applied multivariate statistics for the social sciences*. 5th ed. New York: Routledge; 2012.