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Well-being of mothers with epilepsy with school-aged children

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A R T I C L E I N F O

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ABSTRACT

Purpose: The purpose of the study was to examine different aspects of well-being in mothers with epilepsy with school-aged children.

Methods: In an observational study, mothers, identified from the European Registry of Antiepileptic Drugs and Pregnancy database in the Netherlands, completed questions on epilepsy, the impact of epilepsy on daily functioning, quality of life, behavioral problems, and parenting stress. Descriptive analyses were performed to examine the prevalence of behavioral problems and the impact of epilepsy on different aspects of the mother's daily functioning and family life. We subsequently investigated which factors contributed most to the impact of maternal epilepsy using regression analyses.

Results: One hundred fifty-six (46%) of the 342 invited mothers with epilepsy participated. The majority (89%) had low epilepsy severity, with well-controlled seizures. Internalizing problems within the borderline or clinical range were reported by 23% of the mothers. Behavioral problems were significantly correlated with epilepsy severity (r = 0.26, p = .002), impact of epilepsy on daily functioning (r = 0.32, p < .001), and quality of life (r = -0.52, p < 01). Quality of life was in general good (mean = 8, standard deviation [SD] = 1), with low impact of epilepsy. Epilepsy affected mostly maternal self-confidence, work, and general health. Mothers indicated to experience no to little impact of epilepsy on the relationship with their children, partner, or family. Regression analyses showed that epilepsy severity (1.0, 95% confidence interval [CI]: 0.4 to 1.6; p = .002) and quality of life (-1.3, CI: -2.3 to -0.4; p = .007) were significant contributors to the impact of epilepsy on daily functioning, while other factors (maternal education, family type, behavioral problems, and parenting stress) were nonsignificant.

Discussion: The current study shows that mothers with epilepsy generally fared well. Epilepsy negatively impacted the lives of some mothers, though. As maternal well-being is of importance for mother–child interaction and child development, clinicians should be aware of the impact of epilepsy on maternal psychosocial outcomes and family life of women with epilepsy.

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1. Introduction

Epilepsy is a common neurological disorder occurring in up to 1.0% of the general population [1]. Having epilepsy goes beyond the seizures as it has an important impact on psychosocial functioning of people with epilepsy [2–4]. Women of childbearing age have further challenges around epilepsy, pregnancy, and motherhood [5–9]. We previously showed that mothers with epilepsy experienced more parenting stress compared with mothers from the general population [10].

Epilepsy has a negative impact on the quality of life of women of childbearing age [11,12]. Mothers may have dilemmas between being a good patient and being a good mother [5,13]. Guilt feelings resulting

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from the use of antiepileptic drugs (AEDs) during pregnancy, because of potential teratogenic side effects, may also play a role. Stress and sleep deprivation triggered by the care of an infant may elicit seizures [7,13].

Women with epilepsy need specific information about pregnancy and childbearing, which is not always adequately provided [14–16]. This brings uncertainty, in an already changing period [9,17]. Women with epilepsy have a higher risk of depression and anxiety and more often develop a postpartum depression compared with women without epilepsy [11,18–22]. Seizure frequency and AEDs were found as risk factors [22]. Psychosocial aspects, important for the quality of life, are easily overlooked because of a primary focus on seizures and seizure control [6,22].

There has been increasing attention to the prevalence of psychiatric comorbidities and quality of life before, during, and shortly after pregnancy, but there is limited knowledge about the impact of epilepsy on

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daily functioning during motherhood [6,7]. We attempted to investigate the impact of epilepsy on different aspects of the mother's daily functioning and family life and examined which epilepsy-related factors or psychosocial factors contribute most. We hypothesized that next to epilepsy-related factors, behavioral problems and parenting stress would be important contributors to the impact of maternal epilepsy.

2. Methods

2.1. Study design and participants

In collaboration with the European Registry of Antiepileptic Drugs and Pregnancy (EURAP) the Dutch EURAP & Development study was designed, a prospective observational study of children of mothers with epilepsy. The current study is part of a larger longitudinal study in which long-term effects of prenatal exposure to AEDs on neurocognitive and behavioral development are investigated from a family perspective [23].

Participants were mother–child pairs identified from the EURAP-NL database in the Netherlands, a national, single-center pregnancy register that investigates the prevalence of major congenital malformations following prenatal exposure to AEDs. Women are enrolled by the EURAP-NL center through self-referral or by their health professional. Inclusion criteria were maternal carbamazepine, lamotrigine, levetiracetam, or valproate monotherapy starting before conception and continuing during the entire pregnancy, and the child aged between 6.0 and 7.11 years during the study period. Detailed information on procedures were reported previously [23].

2.2. Measures

Mothers were asked to complete a number of online questionnaires, on demographic information, epilepsy-related information, behavioral and parenting questionnaires, and questions on quality of life and the impact of epilepsy on mother's daily functioning and family life. Participants also received a short intelligence test [24] and had an interview about the child, the family, and maternal epilepsy [23].

2.2.1. Impact of epilepsy on daily functioning and family life

An adapted version of the Impact of Pediatric Epilepsy on the Family (IPES) was used to measure the impact of epilepsy on the mother's daily functioning and family life [25]. We adjusted child epilepsy into maternal epilepsy and changed accordingly some items, for example, instead of school, we asked about work and education (see also Table 4). Mothers were asked to answer 11 questions (e.g., impact on general health, relationship with child(ren), or work and education) on a 4-point severity scale with 0 'not at all' to 3 'a lot'. For each item, the question was 'To what extent did your epilepsy affect your normal daily (family) life in the past three months?'. The higher the score, the higher is the impact of maternal epilepsy on daily functioning with a maximum total score of 33 (range: 0–33). For mothers who thought that one or more of the items was not applicable (i.e., had no spouse or had only one child), the total score was based on only the items answered. Cronbach's alpha was 0.95.

2.2.2. Epilepsy severity

We used epilepsy severity as concept to measure maternal epilepsy [26,27]. Epilepsy severity is a composite variable with total scores between 1 and 9, based on seizure type (1-3), seizure frequency (0-3), and number of AED used (0-3) [26,27]. Generalized tonic–clonic seizures are scored 3, focal seizures 2, and absences 1. Seizure frequency is scored 3 if the mother had weekly or daily seizures, 2 if the mother had monthly seizures, 1 if the mother had seizures once or twice per year, and 0 if no seizures had occurred during the previous year. The number of AEDs are scored 0 when no medication was used, 1 for monotherapy, 2 for polytherapy with two AEDs, and 3 for polytherapy

with three or more AEDs. Scores are summed, with a scoring between 1 and 5 indicating low epilepsy severity and scores ≥ 6 indicating high epilepsy severity [26]. Mothers answered questions about epilepsy activity in the previous twelve months. It was possible that the current number and type of AED were different from during pregnancy.

2.2.3. Quality of life

Mothers were asked to rate their quality of life on a scale of 1–10, with 1 representing the worst and 10 the best possible quality of life.

2.2.4. Adult behavioral problems

To measure possible psychiatric comorbidities, mothers were asked to complete the Adult Self Report (ASR) on emotional behavioral and social problems [28]. The ASR contains 123 items each scored as 'not true' (0), 'somewhat or sometimes true' (1), or 'very true or often true' (2). Each item presents a problem behavior, such as 'I am unhappy, sad, or depressed'. Raw scores are summed and converted into a total behavioral problems score, two broadband scales: internalizing and externalizing problems and eight narrow band problem scales: anxious/ depressed, withdrawn, somatic complaints, thought problems, attention problems, aggressive behavior, rule-breaking behavior, and intrusive behavior. Scores were standardized for gender and age with mean T-score 50 and standard deviation (SD) = 10. Scores can fall within a borderline range (T-score 60–63 for total score and broadband scales, or T-score \geq 64 or T-score \geq 70, respectively).

2.2.5. Parenting stress

The Parenting Stress Questionnaire (OBVL) was used to measure parenting stress [29]. The mother was asked to answer 34 items on a 4-point scale, from 1 'not true' to 4 'very true', about how she experiences her child, how she interacts with her child, and how she feels about her own health (e.g., 'I feel happy with my child'). The OBVL consists of a total parenting stress score and five subscale scores on parentchild relationship problems, parenting problems, depressive mood, parental role restriction, and physical health problems. Higher scores indicate more problems. In a previous paper, we gave descriptive information on the level of parenting stress in mothers with epilepsy [10]. In this study, we used the total parenting stress score as possible predictor of the impact of maternal epilepsy on daily functioning and family life.

2.3. Statistical analyses

Data were analyzed using IBM SPSS Statistics 24. Descriptive analyses were performed to give a comprehensive description of the study population. Demographic and epilepsy-related information were given, for the whole group and for each AED taken during pregnancy. In addition to the total score of the impact of epilepsy on daily functioning and family life, the frequency of response categories of the items of the IPES were examined to explore which area of daily functioning and family life maternal epilepsy was of particular influence. For behavioral problems, percentages of borderline and clinical scores were examined to describe the nature and severity of possible psychiatric comorbidities in mothers with epilepsy.

Regression analyses were performed to examine which factors contribute to the impact of maternal epilepsy on daily functioning and family life. Predictors included were maternal educational level (higher educated or not), family type (one- or two-parent families), epilepsy severity, quality of life, behavioral problems (total score ASR), and parenting stress (total score OBVL). Effects of each predictor were considered separately (direct effects), as well as the effects of all predictors together (total effect). As epilepsy severity is a composite variable, we conducted additional analyses with the three components of epilepsy severity apart (seizure type, seizure frequency, number of AEDs). Analyses were conducted using all available information, without imputation for missing data.

The study was approved by the Medical Ethics Committee of the Academic Medical Center (AMC: NL 45505.018.13). Prior to enrollment of the first participant, the study was registered in the Dutch trial register (www.trialregister.nl: NTR4800). Written informed consent was provided prior to the assessment. When the questionnaire was completed at home, consent was given by e-mail or telephone.

3. Results

In total, 156 (46%) of the 342 invited mothers participated (Fig. 1), of which 26 with two children. The questions on maternal epilepsy and behavioral problems were filled in when the first child within the study was included. For one participating mother, only pregnancy information was available, as the father of the children had filled in the survey part of the study. For four other mothers, information of the behavioral measure, impact of epilepsy, and quality of life were missing. Twenty mothers had chosen 'not applicable' for all items of the IPES, resulting in missing data.

The majority of mothers had completed higher education and were married (Table 1). Most worked part-time. Epilepsy severity was in general low, with a mean score of 3.9 (SD: 1.3, range: 1–7). Only 11% of the mothers had high epilepsy severity (score ≥ 6). Most reported having had no seizures in the previous 12 months. Three percent reported daily seizures. Antiepileptic drug monotherapy was mostly used. Approximately 80% of the mothers still used the same AED as they did during pregnancy. Eight percent of women no longer take AEDs, while 12% used polytherapy with two AEDs.

Overall, mothers had average behavioral scores, with the majority reporting little to no behavioral problems (Table 2). A number of mothers reported clinically relevant behavioral problems, which occurred regularly or often, indicating possible psychiatric comorbidities. The nature of problem behavior was diverse. Mothers who had scores within the borderline range or above the clinical cutoff reported mainly internalizing behavioral problems (consisting of anxious/depressed, withdrawn behavior, and somatic complaints) and attention problems. Behavioral problems were significantly correlated with epilepsy severity, quality of life, and impact of epilepsy, with more behavioral problems associated with higher epilepsy severity, lower quality of life, and more impact of epilepsy on the mother and the family (Table 3).

Mothers rated their quality of life generally as good with a mean of 8.0 (SD: 1.0, range: 4–10). The impact of epilepsy on the mother's daily functioning and family life was in general low (Table 4). When we examined on which aspects maternal epilepsy impacted, we found that their epilepsy affected mostly their self-confidence, followed by work and education and general health. Mothers indicated that their epilepsy had no or little effect on their relationship with their children, partner, friends, or family. Some mothers did, however, report that their epilepsy had an impact on activities with the family.

Regression analyses showed that epilepsy severity and quality of life were significant predictors of the impact of maternal epilepsy, while maternal education, family type, behavioral problems, and parenting stress were nonsignificant (Table 5). For behavioral problems and parenting stress, significant direct effects were found, but after entering the other predictors to the model, epilepsy severity and quality of life were found to be the most important contributors.

Additional analyses with the three components of epilepsy severity separate (seizure type, seizure frequency, number of AEDs) showed that seizure frequency contributed most and was found to be significant, while seizure type and number of AEDs were nonsignificant predictors (not shown, available on request).

4. Discussion

We found that mothers with school-aged children generally fared well, with well-controlled seizures. Epilepsy seems to play a minimal role in their lives. Some mothers, however, indicated that epilepsy had a negative impact on several aspects of their well-being and family life. Epilepsy severity was significantly related to behavioral problems



Fig. 1. Flowchart Dutch EURAP & Development study - number of participating mothers.

Table 1

Demographic and epilepsy-related information for all mothers and by antiepileptic drug used during pregnancy.

All mothersVPACBZLTGLEVSample size Age at assessment, years, mean (SD)15623357325Age at assessment, years, mean (SD)38 (4)40 (3)39 (5)37 (4)38 (4)Maternal education, n (%)13 (57%)17 (49%)44 (60%)16 (64%)Vocational education56 (36%)9 (39%)16 (46%)25 (34%)6 (24%)Lower education10 (6%)1 (4%)2 (6%)4 (5%)3 (12%)Maternal IQ, mean (SD) ^a 104 (14)104 (13)100 (17)104 (13)108 (15)Married104 (67%)16 (70%)21 (60%)50 (68%)17 (68%)Living together35 (22%)4 (17%)10 (29%)16 (22%)5 (20%)Divorced4 (3%)2 (9%)-2 (3%)-Single parent13 (8%)1 (4%)4 (11%)5 (7%)3 (12%)Number of children, n (%) ^b U U U U U U U	Sample size	All mothers	VDA			
Sample size 156 23 35 73 25 Age at assessment, years, mean (SD) 38 (4) 40 (3) 39 (5) 37 (4) 38 (4) Maternal education, n (%) - <th>Sample size</th> <th></th> <th>VPA</th> <th>CBZ</th> <th>LTG</th> <th>LEV</th>	Sample size		VPA	CBZ	LTG	LEV
Age at assessment, years, mean (SD) 38 (4) 40 (3) 39 (5) 37 (4) 38 (4)Maternal education, n (%)Higher education 90 (58%) 13 (57%) 17 (49%) 44 (60%) 16 (64%)Vocational education 56 (36%) 9 (39%) 16 (46%) 25 (34%) 6 (24%)Lower education 10 (6%) 1 (4%) 2 (6%) 4 (5%) 312% Maternal IQ, mean (SD) ^a 104 (14) 104 (13) 100 (17) 104 (13) 108 (15)Married 104 (67%) 16 (70%) 21 (60%) 50 (68%) 17 (68%)Living together 35 (22%) 4 (17%) 10 (29%) 16 (22%) 5 (20%)Divorced 4 (3%) 2 (9%) $ 2$ (3%) $-$ Single parent 13 (8%) 1 (4%) 4 (1%) 5 (7%) 3 (12%)Number of children, n (%) ^b $ 26$ (17%) 8 (35%) 7 (20%) 8 (11%) 3 (12%)		156	23	35	73	25
Maternal education, n (%)Higher education90 (58%)13 (57%)17 (49%)44 (60%)16 (64%)Vocational education56 (36%)9 (39%)16 (46%)25 (34%)6 (24%)Lower education10 (6%)1 (4%)2 (6%)4 (5%)3 (12%)Maternal IQ, mean (SD) ^a 104 (14)104 (13)100 (17)104 (13)108 (15)Married104 (67%)16 (70%)21 (60%)50 (68%)17 (68%)Living together35 (22%)4 (17%)10 (29%)16 (22%)5 (20%)Divorced4 (3%)2 (9%)-2 (3%)-Single parent13 (8%)1 (4%)4 (1%)5 (7%)3 (12%)Number of children, n (%) ^b 2 (3%)-One26 (17%)8 (35%)7 (20%)8 (11%)3 (12%)	Age at assessment, years, mean (SD)	38 (4)	40 (3)	39 (5)	37 (4)	38 (4)
Higher education90 (58%)13 (57%)17 (49%)44 (60%)16 (64%)Vocational education56 (36%)9 (39%)16 (46%)25 (34%)6 (24%)Lower education10 (6%)1 (4%)2 (6%)4 (5%)3 (12%)Maternal IQ, mean (SD) ^a 104 (14)104 (13)100 (17)104 (13)108 (15)Married104 (67%)16 (70%)21 (60%)50 (68%)17 (68%)Living together35 (22%)4 (17%)10 (29%)16 (22%)5 (20%)Divorced4 (3%)2 (9%)-2 (3%)-single parent13 (8%)1 (4%)4 (1%)5 (7%)3 (12%)Number of children, n (%) ^b 026 (17%)8 (35%)7 (20%)8 (11%)3 (12%)	Maternal education, n (%)					
Vocational education $56 (36\%)$ $9 (39\%)$ $16 (46\%)$ $25 (34\%)$ $6 (24\%)$ Lower education $10 (6\%)$ $1 (4\%)$ $2 (6\%)$ $4 (5\%)$ $3 (12\%)$ Maternal IQ, mean (SD) ^a $104 (14)$ $104 (13)$ $100 (17)$ $104 (13)$ $108 (15)$ Marital status, n (%) v v v v v Married $104 (67\%)$ $16 (70\%)$ $21 (60\%)$ $50 (68\%)$ $17 (68\%)$ Living together $35 (22\%)$ $4 (17\%)$ $10 (29\%)$ $16 (22\%)$ $5 (20\%)$ Divorced $4 (3\%)$ $2 (9\%)$ $ 2 (3\%)$ $-$ Single parent $13 (8\%)$ $1 (4\%)$ $4 (11\%)$ $5 (7\%)$ $3 (12\%)$ Number of children, n ($\%$) ^b v v v v v v One $26 (17\%)$ $8 (35\%)$ $7 (20\%)$ $8 (11\%)$ $3 (12\%)$	Higher education	90 (58%)	13 (57%)	17 (49%)	44 (60%)	16 (64%)
Lower education 10 (6%) 1 (4%) 2 (6%) 4 (5%) 3 (12%) Maternal IQ, mean (SD) ^a 104 (14) 104 (13) 100 (17) 104 (13) 108 (15) Married 104 (67%) 16 (70%) 21 (60%) 50 (68%) 17 (68%) Living together 35 (22%) 4 (17%) 10 (29%) 16 (22%) 5 (20%) Divorced 4 (3%) 2 (9%) - 2 (3%) - Single parent 13 (8%) 1 (4%) 4 (11%) 5 (7%) 3 (12%) Number of children, n (%) ^b - - 2 (3%) - One 26 (17%) 8 (35%) 7 (20%) 8 (11%) 3 (12%)	Vocational education	56 (36%)	9 (39%)	16 (46%)	25 (34%)	6 (24%)
Maternal IQ, mean (SD) ^a 104 (14) 104 (13) 100 (17) 104 (13) 108 (15) Married 104 (67%) 16 (70%) 21 (60%) 50 (68%) 17 (68%) Living together 35 (22%) 4 (17%) 10 (29%) 16 (22%) 5 (20%) Divorced 4 (3%) 2 (9%) - 2 (3%) - Single parent 13 (8%) 1 (4%) 4 (11%) 5 (7%) 3 (12%) Number of children, n (%) ^b - - 2 (9%) - 3 (12%)	Lower education	10 (6%)	1 (4%)	2 (6%)	4 (5%)	3 (12%)
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Married 104 (67%) 16 (70%) 21 (60%) 50 (68%) 17 (68%) Living together 35 (22%) 4 (17%) 10 (29%) 16 (22%) 5 (20%) Divorced 4 (3%) 2 (9%) - 2 (3%) - Single parent 13 (8%) 1 (4%) 4 (11%) 5 (7%) 3 (12%) Number of children, n (%) ^b One 26 (17%) 8 (35%) 7 (20%) 8 (11%) 3 (12%)	Marital status, n (%)					
Living together 35 (22%) 4 (17%) 10 (29%) 16 (22%) 5 (20%) Divorced 4 (3%) 2 (9%) - 2 (3%) - Single parent 13 (8%) 1 (4%) 4 (11%) 5 (7%) 3 (12%) Number of children, n (%) ^b - - 5 (7%) 3 (12%) One 26 (17%) 8 (35%) 7 (20%) 8 (11%) 3 (12%)	Married	104 (67%)	16 (70%)	21 (60%)	50 (68%)	17 (68%)
Divorced 4 (3%) 2 (9%) - 2 (3%) - Single parent 13 (8%) 1 (4%) 4 (11%) 5 (7%) 3 (12%) Number of children, n (%) ^b - -	Living together	35 (22%)	4 (17%)	10 (29%)	16 (22%)	5 (20%)
Single parent 13 (8%) 1 (4%) 4 (11%) 5 (7%) 3 (12%) Number of children, n (%) ^b 26 (17%) 8 (35%) 7 (20%) 8 (11%) 3 (12%)	Divorced	4 (3%)	2 (9%)	-	2 (3%)	-
Number of children, n (%) ^b 26 (17%) 8 (35%) 7 (20%) 8 (11%) 3 (12%)	Single parent	13 (8%)	1 (4%)	4 (11%)	5 (7%)	3 (12%)
One 26 (17%) 8 (35%) 7 (20%) 8 (11%) 3 (12%)	Number of children, n (%) ^b					
	One	26 (17%)	8 (35%)	7 (20%)	8 (11%)	3 (12%)
Two 94 (60%) 8 (35%) 25 (71%) 48 (66%) 13 (52%)	Two	94 (60%)	8 (35%)	25 (71%)	48 (66%)	13 (52%)
Three 29(19%) 5 (22%) 3 (9%) 15 (21%) 6 (24%)	Three	29(19%)	5 (22%)	3 (9%)	15 (21%)	6 (24%)
Four or more 7 (4%) 2 (8%) – 2 (2%) 3 (12%)	Four or more	7 (4%)	2 (8%)	-	2 (2%)	3 (12%)
Nationality, Dutch, n (%) 150 (96%) 23 (100%) 35 (100%) 69 (95%) 23 (92%)	Nationality, Dutch, n (%)	150 (96%)	23 (100%)	35 (100%)	69 (95%)	23 (92%)
Employment, n (%) ^c	Employment, n (%) ^c					
Unemployed 26 (17%) 3 (13%) 6 (17%) 13 (18%) 4 (17%)	Unemployed	26 (17%)	3 (13%)	6 (17%)	13 (18%)	4 (17%)
Less than 10 h per week 10 (6%) – 4 (11%) 5 (7%) 1 (4%)	Less than 10 h per week	10 (6%)	_	4 (11%)	5 (7%)	1 (4%)
10–20 h per week 36 (23%) 5 (22%) 7 (20%) 17 (23%) 7 (29%)	10–20 h per week	36 (23%)	5 (22%)	7 (20%)	17 (23%)	7 (29%)
21–30 h per week 53 (34%) 7 (30%) 13 (37%) 25 (34%) 8 (33%)	21–30 h per week	53 (34%)	7 (30%)	13 (37%)	25 (34%)	8 (33%)
31–40 h per week 27 (17%) 8 (35%) 4 (11%) 12 (16%) 3 (13%)	31–40 h per week	27 (17%)	8 (35%)	4 (11%)	12 (16%)	3 (13%)
More than 40 h per week 3 (2%) – 1 (3%) 1 (1%) 1 (4%)	More than 40 h per week	3 (2%)	_	1 (3%)	1 (1%)	1 (4%)
Seizure type, n (%) ^c	Seizure type, n (%) ^c					
Generalized tonic-clonic seizures 92 (59%) 18 (78%) 20 (57%) 40 (55%) 14 (56%)	Generalized tonic-clonic seizures	92 (59%)	18 (78%)	20 (57%)	40 (55%)	14 (56%)
Focal seizures 34 (22%) 2 (9%) 10 (29%) 17 (23%) 5 (20%)	Focal seizures	34 (22%)	2 (9%)	10 (29%)	17 (23%)	5 (20%)
Absences 30 (19%) 3 (13%) 5 (14%) 16 (22%) 6 (24%)	Absences	30 (19%)	3 (13%)	5 (14%)	16 (22%)	6 (24%)
Seizure frequency past 12 months ^c	Seizure frequency past 12 months ^c				× ,	
None 113 (73%) 22 (96%) 23 (66%) 52 (71%) 16 (67%)	None	113 (73%)	22 (96%)	23 (66%)	52 (71%)	16 (67%)
Once or twice per year 19 (12%) 1 (4%) 7 (20%) 7 (10%) 4 (16%)	Once or twice per year	19 (12%)	1 (4%)	7 (20%)	7 (10%)	4 (16%)
Monthly 11 (7%) – 2 (6%) 7 (10%) 2 (8%)	Monthly	11 (7%)	_ ` ` `	2 (6%)	7 (10%)	2 (8%)
Weekly or daily 13 (8%) – 3 (9%) 7 (10%) 3 (12%)	Weekly or daily	13 (8%)	_	3 (9%)	7 (10%)	3 (12%)
Current epilepsy medication, n (%) ^{c,d}	Current epilepsy medication, n (%) ^{c,d}					
None 13 (8%) 1 (4%) 4 (11%) 8 (11%) -	None	13 (8%)	1 (4%)	4 (11%)	8 (11%)	-
Monotherapy 123 (79%) 20 (87%) 28 (80%) 53 (73%) 22 (92%)	Monotherapy	123 (79%)	20 (87%)	28 (80%)	53 (73%)	22 (92%)
Polytherapy with two AED 19 (12%) 2 (9%) 3 (9%) 12 (16%) 2 (8%)	Polytherapy with two AED	19 (12%)	2 (9%)	3 (9%)	12 (16%)	2 (8%)
Polytherapy with three or more AED – – – – – – – – – – –	Polytherapy with three or more AED	_	_	_	_	_
Epilepsy severity, mean (SD) 3.9 (1.3) 3.7 (0.8) 3.9 (1.3) 4.0 (1.4) 4.1 (1.3)	Epilepsy severity, mean (SD)	3.9 (1.3)	3.7 (0.8)	3.9 (1.3)	4.0 (1.4)	4.1 (1.3)

Note. VPA = valproate, CBZ = carbamazepine, LTG = lamotrigine, LEV = levetiracetam.

^a Maternal IQ was measured with the Wechsler Adult Intelligence Scale (WAIS-III-NL), missing for 18 mothers.

^b Twenty-six mothers participated with two children within the Dutch EURAP & Development study.

^c For one mother, information on these variables was missing. Maternal educational level is based on information from the EURAP-NL pregnancy register. Seizure type, frequency, and current medication is based on information from the mother.

^d The majority (80%) of the women were still on the same antiepileptic drug as they did during pregnancy.

Table 2

Mean, standard deviations (standard scores), and percentages of mothers within the borderline range and above the clinical cutoff on behavior outcome measures.

Adult Self Report	N = 151			
	М	SD	Borderline	Clinical
Total behavioral problems (Tot)	50.0	9.2	9.9%	6.0%
Internalizing problems (INT)	52.3	9.3	12.6%	10.6%
Externalizing problems (EXT)	49.2	9.0	8.6%	4.6%
I Anxious/Depressed	54.8	5.4	5.3%	0.7%
II Withdrawn	54.2	5.4	7.3%	1.3%
III Somatic complaints	56.4	6.6	9.3%	3.3%
IV Thought problems	53.7	5.3	4.6%	2.0%
V Attention problems	58.4	7.7	12.6%	6.6%
VI Aggressive behavior	54.6	5.8	6.0%	2.6%
VII Rule-breaking behavior	53.8	5.0	2.6%	2.0%
VIII Intrusive behavior	51.7	2.9	1.3%	0%

Note. N = sample size; M = mean; SD = standard deviation; Maternal behavioral problems were measured with the Adult Self Report (ASR); mean T-score 50, SD 10. Cutoff scores: Narrow band (I t/m VIII): T-score 65–69 = borderline; \geq 70 = clinical; Broadband (INT, EXT, Tot): T-score 60–63 = borderline; \geq 64 = clinical. and higher impact of maternal epilepsy on daily functioning. The impact of maternal epilepsy on daily functioning was also associated with lower quality of life. For those mothers with active epilepsy, the burden of epilepsy also appears to affect motherhood [2,4,9].

Internalizing problems within the borderline or clinical range were reported by a quarter of the mothers. As internalizing problems consist of anxiety, depression, withdrawal, and somatic complaints, this prevalence seems comparable with studies that reported on anxiety and depression in women with epilepsy [11,22]. Those studies were, however, on women during or shortly after pregnancy, in which levels

Table 3

Relationship between maternal behavioral problems, epilepsy severity, quality of life, and impact of maternal epilepsy on daily functioning and family life.

	1	2	3	4
1. Total behavioral problems 2. Epilepsy severity 3. Quality of life 4. Impact of maternal epilepsy	- 0.26** - 0.52** 0.32**	- -0.15* 0.35**	- - 0.40**	_

* *p* < .05.

** *p* < .01.

Mean and standard deviations of impact of epilepsy on daily functioning and quality of life, and frequency of response categories on IPES.

	N = 151	To what extend did your epilepsy affect your normal daily (family) life in the past three month				past three months?
IPES (0-3)	M (SD)	Not at all (0)	A little (1)	Quite (2)	A lot (3)	Not applicable
1. General health	0.3 (0.6)	102 (67.5%)	23 (15.2%)	5 (3.3%)	1 (0.7%)	20 (13.2%)
2. Relationship with child(ren)	0.1 (0.5)	120 (79.5%)	8 (5.3%)	3 (2.0%)	1 (0.7%)	19 (12.6%)
3. Relationship between children	0.1 (0.4)	115 (76.2%)	3 (2.0%)	1 (0.7%)	1 (0.7%)	31 (20.5%)
4. Relationship with partner/spouse	0.2 (0.5)	106 (70.2%)	14 (9.3%)	4 (2.6%)	1 (0.7%)	26 (17.2%)
5. Relationship with friends/family	0.1 (0.5)	117 (77.5%)	7 (4.6%)	3 (2.0%)	1 (0.7%)	23 (15.2%)
6. Social contacts: acceptance by others	0.1 (0.5)	114 (75.5%)	9 (6.0%)	2 (1.3%)	2 (1.3%)	24 (15.9%)
7. Social contacts: number of activities	0.2 (0.6)	107 (70.9%)	14 (9.3%)	2 (1.3%)	4 (2.6%)	24 (15.9%)
8. Work and education	0.4 (0.8)	94 (62.3%)	17 (11.3%)	5 (3.3%)	6 (4.0%)	29 (19.2%)
9. Your self-confidence	0.4 (0.8)	87 (57.6%)	31 (20.5%)	5 (3.3%)	5 (3.3%)	23 (15.2%)
10. Loss of future expectations	0.2 (0.6)	107 (70.9%)	13 (8.6%)	6 (4.0%)	1 (0.7%)	24 (15.9%)
11. Activities with family	0.3 (0.5)	100 (66.2%)	23 (15.2%)	5 (3.3%)	0 (0.0%)	23 (15.2%)
	M (SD)	Range				
Total score impact of maternal epilepsy (0-33) ^a	2.4 (4.6)	0-24				
Quality of life (1–10)	8.0 (1.0)	4-10				

Note. N = sample size; M = mean; SD = standard deviation. IPES = Adapted version of the Impact of Pediatric Epilepsy on the Family.

^a Total score of IPES is based on 131 mothers, because 20 mothers had indicated 'not applicable' on all items.

of stress might be higher. Our study shows that internalizing problems also occur in mothers with school-aged children. Attention problems were also frequently reported by mothers. Cognitive problems are common in people with epilepsy [30]. The percentage of attention problems in the current study was, however, substantially lower than in children with epilepsy [27,31]. This difference may be due to a child's brain still being in development or because adults have developed more effective coping strategies. Attention problems, nevertheless, can have an impact on the daily lives of women with epilepsy.

Epilepsy severity and quality of life were found to be significant predictors of the impact of maternal epilepsy on daily functioning and family life, whereby seizure frequency showed to be the significant component of epilepsy severity. Against expectations, behavioral problems and parenting stress showed no significant contribution. They first showed a significant direct effect, but when all predictors were entered to the model, epilepsy severity and quality of life were found to be the more important contributors. Parenting stress and behavioral problems are indicative of maternal emotional well-being [32] and were found to be important predictors of child behavioral problems [10]. With respect to the impact of maternal epilepsy on daily functioning, epilepsy-related factors (such as seizure frequency) seem more important. Although the different factors are related, the outcome measure determines which factors have the greatest contribution. It seems a logical result that specific epilepsy-related factors contributed the most to the impact of maternal epilepsy on daily functioning [33,34]. This was different for

Table 5

Regression analyses with total score of impact of maternal epilepsy on daily functioning as dependent variable.

Total score IPES	Total effect ^a	Direct effect ^b		
	B (SE)	95% CI	p value	p value
Constant Maternal education Family type Epilepsy severity Quality of life Total behavioral problems Total parenting stress	7.3 (6.2) -0.1 (0.7) -0.8 (1.2) 1.0 (0.3) -1.3 (0.5) 0.1 (0.1) 0.01 (0.1)	-4.9 to 19.6 -1.5 to 1.4 -3.2 to 1.6 0.4 to 1.6 -2.3 to $-0.4-0.1$ to 0.2 -0.1 to 0.1	.239 .912 .496 .002** .007** .348 913	- .860 .491 <.001*** <.001*** <.001*** <.001***

Note. IPES = Adapted version of the Impact of Pediatric Epilepsy on the Family. B = un-standardized coefficients, SE = standard error, CI = Confidence Interval.

^a Regression analyses with all predictors together, giving total effect on impact of maternal epilepsy on daily functioning.

^b Regression analyses with each predictor separately to show the direct effect of a predictor on impact of maternal epilepsy on daily functioning.

** *p* < .01. *** *p* < .001. findings with regard to child behavioral problems where parenting and parental psychopathology were the most important contributors [10,27,35].

The impact of maternal epilepsy on the relationship with the partner and children was not experienced as problematic: mothers indicated that they experienced no or little impact in this realm. The majority of mothers were married or lived together. A previous study showed that single parenthood had a more negative influence on life satisfaction [9]. In our analyses, family type – one- or two-parent families – was not found to be a significant predictor of the impact of epilepsy. In a recent review, it was concluded that epilepsy has a severe impact on family life; however, the influence of seizures on the partner was found to be hardly studied [36]. The burden of epilepsy may affect parenting via the marital relationship. Impact of seizures may also apply to the children. For example, they may experience fear or anxiety from the perception that the mother might pass away during the seizure. This may affect the child's mental health and may be a risk factor for posttraumatic stress symptoms in children.

This study has a number of limitations. Our inclusion rate was 46%, only 156 of the 342 invited mothers participated, which may have caused potential selection bias with a tendency to higher educated mothers. This study does, therefore, not shed light on how lower educated mothers with epilepsy are faring. In addition, we invited women from the pregnancy registers, which only reach part of the women with epilepsy, also making generalizability of results difficult. Most women had a low epilepsy severity on monotherapy. The influence of epilepsy in women with severe epilepsy and polytherapy is found to be greater [12,22]. We had no information on epilepsy duration. Quality of life was rated on a single item. This may possibly not reliably reflect quality of life as a multidimensional construct, although it must be noted that capturing health or health-related quality of life via a single item has yielded reliable and valid outcomes [37,38].

Future research should include semistructured interviews with mothers on the influence of epilepsy on motherhood, to improve insight into their experiences [5,13]. We spoke with the mothers about their epilepsy, but not in a structured manner. Many mothers indicated that their epilepsy played a minor role in their life. Children often did not know about their epilepsy, except that the mother took 'pills'. This was different, however, when the epilepsy was active and the mother had seizures, whether or not in the presence of the child. Mothers indicated that when the child had seen a seizure, this had a large impact and sometimes even had become a traumatic event for the child (for which one child in our study also received trauma treatment) [39].

As maternal well-being is of importance for mother–child interaction [6], clinicians should keep an eye on the impact of epilepsy on the psychosocial functioning and family life of women with epilepsy [40]. Future research should focus as well on the role of the partner [36]. The quality of life can often be improved with minimal interventions [41], which is also in the interest of the children of mothers with epilepsy.

Declaration of competing interest

YH-M, FO, and RR have no disclosures to report. DL has – in the past (2000–2002) – received research grants from Janssen-Cilag, GlaxoSmithKline, Pfizer, and the Netherlands Epilepsy Foundation, to start-up the basic EURAP study in the Netherlands.

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