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Emotional well-being in children with epilepsy: Family factors as mediators and moderators

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FULL-LENGTH ORIGINAL RESEARCH

Emotional well-being in children with epilepsy: Family factors as mediators and moderators

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SUMMARY

Objective: **Our objective was to examine the relationships of factors associated with children's emotional well-being 2 years after diagnosis, and to examine if these relationships are mediated or moderated by family factors.**

Methods: **Data came from a multicenter prospective cohort study of children with newly diagnosed epilepsy from across Canada (Health-Related Quality of Life in Children with Epilepsy Study; HERQULES, n = 373). Emotional well-being was assessed using the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). The relationships between clinical factors, family factors, and emotional well-being were assessed using multiple regression analyses.**

Results: **Family functioning, family stress, and repertoire of resources that the families had to adapt to stressful events were significantly associated with poor emotional well-being 2 years after diagnosis ($p < 0.05$) in the multivariable analysis. The effect of parental depressive symptoms was partially mediated by family functioning and family stress ($p < 0.01$ and $p = 0.02$, respectively). Family resources acted as a moderator in the relationship between severity of epilepsy and emotional well-being ($p < 0.05$).**

Significance: **Based on our findings, efforts to strengthen the family environment may warrant attention. We suggest that clinicians take a family centered care approach by including families in treatment planning. Family centered care has been shown to improve family well-being and coping and in turn may reduce the impact of clinical factors on emotional well-being to improve long-term health-related quality of life.**

Shane W. Goodwin is a postdoctoral fellow at the University of Waterloo.

KEY WORDS: **Children, Epilepsy, Emotional well-being, Health-related quality of life, Family environment.**

Childhood epilepsy is associated with an elevated risk of poor health-related quality of life (HRQoL).[1,2] Compared to healthy children, psychosocial issues are more frequent in children with epilepsy, with increased risks of emotional and behavioral disorders, including depression, anxiety, and poor self-esteem.[3–6] One domain of HRQoL, emotional well-being (EWB), represents an overall view of emotional functioning through the inclusion of both positive affects and negative affects.[7] In this way, EWB is conceptualized as a broad measure of emotional functioning, including multiple aspects of mental health such as items of depression, anxiety, anger, happiness, or confidence. Changes in EWB highlight the effect that a disease or disorder has on an individual's emotional functioning.

Research has been inconsistent regarding factors associated with poor EWB in children with epilepsy. Some of the clinical factors that have been suggested to be associated with poor EWB include frequency of seizures,[8,9] severity of epilepsy,[10,11] and use of antiepileptic drugs (AEDs).[9,12] Although little research has been conducted that investigates the role of the family on EWB in children with epilepsy, there is evidence that poor family mastery,[13] poor parental emotional support,[13] low parental confidence,[13] poor family adjustment and restrictive

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KEY POINTS

- Family functioning, family stress, and family resources were associated with poor emotional well-being 2 years after diagnosis
- Parental depressive symptoms were partially mediated by family functioning and family stress
- Family resources acted as a moderator in the relationship between severity of epilepsy and emotional well-being
- Given the strong associations of family environment with emotional well-being, the inclusion of the family in the management of treatment may help improve long-term emotional well-being

parenting,[14] and negative child–parent or child–family interactions[14–16] are each associated with increased risks of behavioral and emotional problems. Available evidence also suggests that specific family factors may act as mediators between clinical factors and health outcomes. In one study, parents who believed their child would be stigmatized or who had rigid decision making styles that placed restrictions on the child reported higher levels of behavioral problems in their child.[17] This same study also found that in children with simple partial seizures, factors related to parent–child interactions acted as a mediator between the effects of the seizures and levels of behavioral problems.[17] Other possible mediation mechanisms for the effects of factors on emotional or behavioral problems have been suggested such as perception of the child as in poor health,[18] a perception of the child as clumsy,[18] poor perception of support,[19] poor emotional adjustment,[19] negative maternal attitude toward epilepsy,[20] and high family stress.[20] In these findings, it was not always epilepsy itself that produced the effects but rather reactions to epilepsy. This suggests the importance of strengthening the family unit at and after diagnosis to limit or weaken the negative effects of epilepsy on the risk of behavioral and emotional problems, and overall HRQoL.

Our objective was to examine the relationships of clinical factors with children's EWB 2 years after diagnosis to determine if these relationships are mediated or moderated by family factors.

METHODS

Data source and participants

Data were obtained from the Health-Related Quality of Life in Children with Epilepsy Study (HERQULES), a multicenter prospective cohort study of children ages 4 to 12 years with new-onset epilepsy. A two-stage clustered sampling strategy was used to recruit pediatric neurologists and parents from across Canada. A total of 456 eligible patients were identified, and their parents were asked to participate in a series of self-administered, mailed questionnaires and to provide consent for their child's neurologist to provide clinical information about their child's epilepsy. Data were collected from participating parents and neurologists at four times over the 2 years after diagnosis: baseline (as close as possible to the time of diagnosis) and approximately 6, 12, and 24 months later. A more detailed description of the HERQULES methodology has been reported previously.[1,21] Results investigating overall HRQoL using the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE) have been previously reported.[21,22]

Measures

Emotional well-being as a health outcome

Our working definition of EWB followed that of the World Health Organization (WHO), where EWB is conceived as a broad measure of emotional functioning to encompass a complete state of well-being rather than simply an absence of infirmity.[23] With this definition, a measure of EWB should be a balance of positive and negative affect.[7] Although it is difficult to identify a measure that perfectly meets this definition, it is important that a measure includes multiple components of mental health, both for positive and for negative effects, to provide a broad view of the overall mental health of an individual. A subscale from the QOLCE[21,24] was used to assess EWB in this study, which is consistent with the WHO definition of EWB. The QOLCE is an epilepsy-specific, parent-report measure of HRQoL for children ages 4–18 years. This study employed the 55-item version, QOLCE-55.[21] The QOLCE-55 assesses HRQoL across four domains, with one assessing EWB. The EWB subscale of the QOLCE-55 contains 17 items assessing the multiple components of EWB. Each item is rated on a five-point Likert scale and then transformed to a score from 0 (low functioning) to 100 (high functioning). In HERQULES, the QOLCE-55 has demonstrated high internal consistency reliability, with a Cronbach's alpha of 0.96 overall and 0.88 for the EWB subscale at baseline.

Family factors

Parental Depressive Symptoms: Parental depressive symptoms were assessed using the Center for Epidemiological Studies Depression Scale (CES-D),[25] a 20-item self-report instrument measuring depressive symptoms using a four-point Likert scale. CES-D assesses the frequency of depressive symptoms over the preceding 4 weeks, resulting in a total score from 0 to 60, with higher scores representing more depressive symptoms. In HERQULES, the internal consistency reliability was good, with Cronbach's alpha ranging from 0.75 to 0.80 across the four time points.

Family Functioning: Family functioning was measured with the Family Adaptability, Partnership, Growth, Affection, and Resolve (APGAR).[26] APGAR has five items measured on a five-point Likert scale ranging from 0 (hardly ever) to 4 (almost always) and a total score (0 to 20) indicating the level of satisfaction with family functioning (where higher scores represent greater family satisfaction). In HERQULES, the internal consistency reliability of APGAR was high with Cronbach's alpha ranging from 0.86 to 0.89 across the four time points.

Family stress: The Family Inventory of Life Events and Changes (FILE) was used to measure family stress.[27] FILE is a 71-item instrument assessing family stress, with a total score of 0 to 71, where higher scores indicate greater levels of stress on the family. In HERQULES, the internal consistency reliability of FILE was high with Cronbach's alpha ranging from 0.83 to 0.98 across the four time points.

Family Resources: Family resources were assessed using the Family Inventory of Resources for Management (FIRM).[28] FIRM assesses resources that families have available to aid their adaptation to stressful events. Family Mastery and Health (20 items) and Extended Family Social Support (4 items) were included in HERCULES, measured on a four-point Likert scale, with higher scores indicate more resources. In HERQULES, the internal consistency reliability was high with Cronbach's alpha ranging from 0.91 to 0.93 for the Family Mastery and Health subscale, and from 0.44 to 0.54 for the Extended Family Support subscale, across the four time points.

Clinical factors

Information regarding epilepsy factors was collected through a neurologist report. Included in these reports was the Global Assessment of Severity of Epilepsy (GASE),[29] a single-item measure to rate the severity of epilepsy on a seven-point scale ranging from 1 (extremely severe) to 7 (not severe at all). Inter-rater reliability has been demonstrated previously as high, with weighted kappa values for two independent raters of 0.90 (95% confidence interval [CI] 0.82–0.98).[29]

Neurologists reported on other aspects of epilepsy including frequency of seizures, the number of AEDs, and type of seizure. Type of seizure was coded in two ways using the International League Against Epilepsy (ILAE) Classification and Terminology:[30,31] broadly as generalized or partial. Neurologists reported on the severity of behavioral and cognitive problems using a four-point and five-point Likert scale, respectively (behavior problems: none, mild, moderate, severe; cognitive problems: none, borderline, mild, moderate, severe). In this study, both presence of behavioral problems and cognitive problems were dichotomized as present or absent, as our interests were simply to examine the difference between those with and those without the presence of behavioral or cognitive problems rather than examine any differences in severity of problems.

Demographic characteristics

Demographic characteristics of families, including parent's age, education, living with a spouse, employment status, and household income were also collected.

Statistical analysis

Mplus 7.1 (Muthén & Muthén, 2012; https://www.statmodel.com) was used for all analyses. Family functioning, stress, and resources, as well as parental depressive scores, were mean-centered for ease of interpretation. Clinical factors and family factors were analyzed from baseline while child EWB was measured at baseline and 24-months. Socioeconomic factors were included from baseline as confounders. EWB at 24 months was used as the outcome, whereas EWB at baseline was used as an adjustment allowing the outcome to be conceptualized as the *change in emotional well-being* across the 24 months. Univariable linear regression and Pearson correlation were used initially to assess unadjusted associations between factors and outcome before multivariable analyses. Factors that had a p-value of <0.20 during univariable modeling or were identified a priori as being of interest based on previous research were chosen to be included in multivariable analysis. A higher significance value threshold during variable selection was chosen to increase the likelihood of retaining important variables that showed nonsignificance due to lack of included confounders.[32,33]

Several models were examined to identify the effects of clinical factors and mediation and moderation effects of family factors on EWB at 24 months. In model 1, the baseline model, only clinical factors and confounders were included. Models 2, 3, and 4 were each built from the initial model by including family factors to test for possible mediation effects. Model 2 included family functioning and model 3 included family stress. Model 4 examined whether mediation occurred with both factors in the model simultaneously. Moderation effects were assessed using an interaction variable of family resources and each factor. Each interaction was tested separately. Only significant interaction variables at 0.05 thresholds are presented. Model 5 tested for simultaneous mediating and moderating effects. The results of mediation and moderation of each individual factor unadjusted by other factors were also examined.

Mediation effects of family factors on the association between clinical factors and EWB were examined using the Sobel test.[34,35] The Sobel test provided the product of coefficients of each pathway in the mediation model and provides appropriate standard errors to test for statistical significance.[34,35]

RESULTS

Sample characteristics

Of the 456 eligible patients identified, parents of 373 (82%) completed the baseline questionnaire. Of those, 336 completed the 6-month questionnaire, 304 the 12-month questionnaire, and 282 for the 24-month questionnaire. See Figure 1 for a graphical representation of parents' participation and retention.

At baseline, children had a mean age of 7.5 (standard deviation [SD] 2.3) years, with 52% being male. Children had a mean GASE of 5.1, and moderately high EWB, with a baseline EWB of 72.5 (SD 13.2). Mean age of parents was 38.0 (SD 6.1) years, 87% were living with a spouse, 67% were employed, and 67% had completed postsecondary education. Mothers participated as the primary caregivers in most of the surveys returned (91% at both baseline and 2 years after diagnosis). Additional baseline characteristics are reported in Table 1.

Univariable results

Univariable analyses resulted in the following variables being included in the multivariable model: GASE, frequency of seizures, AEDs, presence of behavioral problems (no, yes), presence of cognitive problems (no, yes), and parental depressive symptoms. Confounders included were living with a spouse or partner, parental education, and household income. Univariable results are reported in Table 2.

Mediation effects of family functioning and family stress

Presence of behavioral problems was the only clinical factor to be significantly associated with EWB in multivariable models (Table 3, model 1). Parental depressive symptoms was the only factor to be mediated by family functioning and family stress (Table 3), whereas the presence of behavioral problems was mediated by family functioning when tested individually. Inclusion of family functioning in the model reduced the magnitude of the direct effect of parental depressive symptoms on EWB by 75% (−0.12 vs. −0.03), whereas inclusion of family stress reduced this effect by 33% (−0.08 vs. −0.12). The inclusion of both family factors simultaneously reduced the magnitude of the direct effect by 92% (0.01 vs. −0.12). Family resources were found to partially mediate the effects of both family functioning and family stress on child EWB ($p < 0.002$ for both, see Table 4).

Moderating effects of family resources

An interaction was found between family resources and severity of epilepsy (see Table 3). Children with more severe epilepsy (indicated by a low GASE score) received more benefit from increased family resources.

DISCUSSION

The objective of this study was to examine the relationships among clinical factors and child's EWB 2 years after diagnosis, and to determine whether the effects of factors on EWB are mediated or moderated by family factors. Our results suggest that baseline family functioning, family stress, and family resources are strongly associated with emotional well-being 24 months after diagnosis. We found that the presence of behavioral problems was the only clinical factor to be associated with poor emotional well-being. This finding is not all that surprising given that there was a moderate association between behavioral items in the EWB subscale and the behavioral problems measure based on neurologist-report. We believe that neurologists' reports of behavioral problems likely tap into broader aspects of behavior beyond those items contained within the EWB

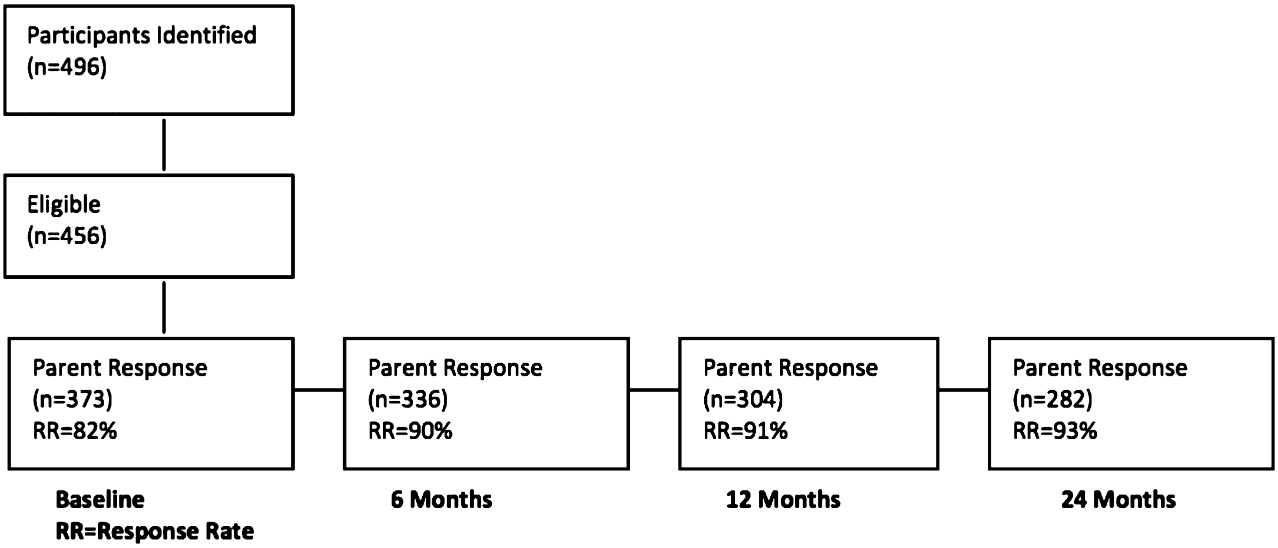

Figure 1.
Participant recruitment and retention.
Epilepsia © ILAE

Table 1. Child and parent characteristics

	Baseline (n = 373)	6 Months (n = 336)	12 Months (n = 304)	24 Months (n = 282)
Child characteristics				
Age, years				
Mean (SD)	7.5 (2.3)	7.9 (2.4)	8.5 (2.3)	9.5 (2.3)
Sex				
Male	52.4	51.5	50.7	51.6
Severity of epilepsy				
Moderately severe or worse	23.1	11.6	8.8	8.3
Somewhat severe or better	76.9	88.4	91.2	91.7
Seizure type				
Partial	59.6	59.0	58.4	57.8
Generalized	38.5	39.2	39.8	39.5
Frequency of seizures, mean (SD)	3.3 (1.7)	1.9 (1.3)	1.7 (1.1)	1.6 (1.0)
Current AED use	67.1	81.0	81.8	76.5
Total AEDs taken, mean (SD)	0.8 (0.7)	1.2 (0.9)	1.3 (1.1)	1.4 (1.3)
Cognitive problems	20.0	23.0	25.5	28.4
Behavioral problems	15.4	23.6	20.7	22.7
QOLCE emotional well-being mean (SD)	72.5 (13.2)	73.8 (12.8)	74.4 (13.0)	75.1 (12.9)
Parent characteristics				
Living with a spouse or partner	87	87	88	88
Household income				
<$59,999	43.7	42.8	37.9	34.6
>$60,000	56.3	57.2	62.1	65.4
Age primary caregiver, mean (SD)	37.7 (6.1)	38.2 (5.8)	39.1 (5.9)	40.3 (5.6)
High school or less	33.5	29.7	26.3	25.2
Vocational, college/university, or postgraduate education	66.5	70.3	73.7	74.8
Employed	67.1	70.7	73.5	77.0
Parental depression	37.2	25.9	24.9	21.4
Resources, FIRM**,** mean (SD)	50.1 (11.1)	51.0 (11.2)	51.0 (11.5)	50.7 (11.5)
Stress, FILE, mean (SD)	9.5 (6.5)	N/A	8.0 (6.0)	7.9 (5.7)
Functioning, APGAR, **mean** (SD)	13.9 (3.8)	14.1 (3.7)	13.9 (4.0)	14.1 (3.9)

Reported as percentages, unless otherwise stated.

Table 2. Univariable analyses with emotional well-being at 2 years examining for possible inclusion into multivariable models

	β (SE)	Pearson correlation
AED use	−1.94 (7.5), p = 0.80	−0.8, p = 0.18
Frequency of seizures	−2.54 (1.8), p = 0.19	−0.11, p = 0.08
Severity of epilepsy (GASE)	2.76 (3.1), p = 0.40	0.09, p = 0.18
Behavioral problems	−14.72 (4.33), p < 0.001	−0.35, p < 0.001
Cognitive problems	−7.36 (4.31), p < 0.05	−0.26, p < 0.001
Depressive symptoms (CES-D)	−0.78 (0.43), p = 0.09	−0.28, p < 0.001
Family functioning (APGAR)	1.62 (1.08), p = 0.15	0.41, p < 0.001
Family stress (FILE)	−1.18 (0.72), p = 0.12	−0.28, p < 0.001
Family resources (FIRM)	1.05 (0.33), p < 0.05	0.43, p < 0.001
Parental income	−1.92 (3.05), p = 0.53	0.10, p = 0.10
Child age	−0.63 (2.35), p = 0.79	−0.001, p = 1.0
Child sex	−0.51 (9.27), p = 0.96	0.01, p = 0.86
Parental education	−6.86 (9.09), p = 0.46	0.03, p = 0.68
Living with a spouse	−2.80 (3.97), p = 0.49	−0.08, p = 0.19
Parental work status	2.92 (11.5), p = 0.80	0.04, p = 0.55

subscale, and as such is a valuable clinical factor. Parental depressive symptoms have been found to be associated with poorer HRQoL in children with epilepsy,[21,36] but did not reach the $p < 0.05$ threshold for statistical significance in our study. We did however find results to suggest that the effect of parental depressive symptoms is mediated indirectly through family factors.

Classification of family factors as mediators or moderators has been examined in a previous study of children with epilepsy.[37] These authors found that proximal family factors

Table 3. Unstandardized multivariable linear regression results assessing mediation and moderation.

	Model 1	Model 2	Model 3	Model 4	Model 5
Intercept	52.09 (8.06)	57.88 (7.85)	54.34 (8.01)	59.61 (7.81)	61.30 (7.61)
AED use	−0.17 (1.17)	−0.46 (1.13)	−0.46 (1.17)	−0.70 (1.12)	−0.72 (1.08)
Frequency of seizures	−0.15 (0.41)	−0.37 (0.39)	−0.16 (0.40)	−0.37 (0.39)	−0.43 (0.38)
Severity of epilepsy (GASE)	0.11 (0.58)	−0.13 (0.56)	0.05 (0.57)	−0.17 (0.55)	−0.10 (0.53)
Behavioral problems	−6.25 (2.07)^a	−5.56 (1.99)^a	−6.10 (2.04)^a	−5.46 (1.97)^a	−5.34 (1.95)^a
Cognitive problems	−3.51 (1.99)	−3.56 (1.92)	−3.55 (1.97)	−3.60 (1.90)	−2.17 (1.85)
Depressive symptoms (CES-D)	−0.12 (0.07)	−0.03 (0.07)	−0.08 (0.07)	0.01 (0.07)	0.05 (0.07)
Family functioning (APGAR)	–	0.85 (0.19)^a	–	0.82 (0.19)^a	0.72 (0.20)^a
Family stress (FILE)	–	–	−0.29 (0.12)^a	−0.25 (0.12)^a	−0.13 (0.12)
Family resources (FIRM)	–	–	–	–	1.03 (0.26)^a
GASE*FIRM interaction	–	–	–	–	−0.16 (0.05)^a
Baseline EWB	0.46 (0.05)^a	0.40 (0.05)^a	0.43 (0.05)^a	0.39 (0.05)^a	0.38 (0.05)^a
Household income	0.65 (0.60)	0.39 (0.58)	0.45 (0.60)	0.22 (0.58)	0.19 (0.58)
Parental education	−1.61 (1.30)	−2.09 (1.26)	−1.51 (1.29)	−1.98 (1.25)	−2.05 (1.20)
Living with a spouse	1.93 (2.31)	2.84 (2.23)	1.90 (2.28)	2.78 (2.21)	2.34 (2.15)

Values denote β-coefficients (standard error).
$^a p < 0.05$.

Table 4. Unstandardized mediating effects on the relationship between parental depressive symptoms and emotional well-being

	Equation 1	Equation 2	*ab*	*Z*-value	P-value
Mediator: family functioning (Model 2)					
Intercept	57.88 (7.85)	−0.01 (0.19)	−0.12 (0.03)	−3.84	0.001
Depressive symptoms	−0.03 (0.07)	−0.14 (0.02)			
Family functioning (APGAR)	0.85 (0.19)				
Mediator: family stress (Model 3)					
Intercept	54.36 (8.02)	0.22 (0.33)	−0.07 (0.03)	−2.30	0.02
Depressive symptoms (CES-D)	−0.08 (0.07)	0.23 (0.03)			
Family stress (FILE)	−0.29 (0.12)				
Mediator: family resources (Model 5)					
Intercept	61.33 (7.61)	0.06 (0.46)	−0.12 (0.04)	−3.08	0.002
Depressive symptoms (CES-D)	0.06 (0.07)	−0.30 (0.05)			
Family stress (FILE)	−0.13 (0.12)	−0.53 (0.08)			
Family resources (FIRM)	1.02 (0.26)				
Intercept	61.33 (7.61)	0.18 (0.33)	−0.03 (0.03)	−1.14	0.256
Depressive symptoms (CES-D)	0.06 (0.07)	0.22 (0.03)			
Family stress (FILE)	−0.13 (0.12)				
Intercept	61.33 (7.61)	0.06 (0.46)	−0.14 (0.04)	−3.17	0.002
Depressive symptoms (CES-D)	0.06 (0.07)	−0.30 (0.05)			
Family functioning (APGAR)	0.72 (0.20)	1.02 (0.14)			
Family resources (FIRM)	1.02 (0.26)				
Intercept	61.33 (7.61)	0.03 (0.19)	−0.10 (0.03)	−3.27	0.001
Depressive symptoms (CES-D)	0.06 (0.07)	−0.13 (0.02)			
Family functioning (APGAR)	0.72 (0.20)				

Values denote β-coefficients (standard error). Equation 1 is obtained from the regression of parental depressive symptoms, family functioning/stress, and emotional well-being. Equation 2 is obtained from the regression of parental depressive symptoms on family functioning/stress. *ab* is the coefficient obtained when multiplying the family functioning/stress coefficient from equation 1 by the depressive symptoms coefficient in equation 2.

(characterized as the way parents and children relate to or interact with one another) mediate the effects of parental depression on children's externalizing problems and delinquent behavior.[37] We had similar findings, where family factors mediated the effects of parental depressive symptoms on children's EWB, likely due to the role that family functioning and family stress play in influencing the nature of parent–child interactions.

Beyond parental depressive symptoms, we found that family factors did not mediate the relationships of any factors with EWB. We did find evidence to suggest that the effects of both family functioning and family stress were partially mediated by family resources. A possible explanation for this is that the repertoire of resources families have to adapt to stressful situations is important in determining their ability to cope. It is reasonable to suggest that near diagnosis these factors play a large role in the child's ability to cope and may result in a closer relationship between parent and child. In this case, resources are acting both as a mediator and moderator and would explain the results obtained. Although this finding has not been examined previously in childhood epilepsy, it is consistent with a study of caregiver health, where increases in primary stressors (physical symptoms) did not directly increase changes in mental health outcomes, but rather it was those psychosocial resources that were found to be related to changes in stress outcomes across time.[38]

We found a significant interaction between the severity of epilepsy and family resources. In this case, children who have more severe epilepsy receive more benefit to their EWB from increases in family resources, particularly if family resources were initially low at baseline. This finding may be useful during decisions of treatment strategies, where children living in families with fewer resources to adapt to or cope with stressful situations are more likely to benefit from interventions aimed at strengthening the family's ability to adapt to epilepsy. This in turn may reduce the impact that severity of epilepsy has on their child's overall EWB. A focus on allocation of resources to interventions at diagnosis may lead to better success in improving EWB while optimizing resource use.

A major strength of our study was the ability to include multiple aspects of the family environment in addition to clinical data regarding epilepsy in a longitudinal study. In contrast with previous research,[37] we could examine the impact of the family environment near the diagnosis of epilepsy and examine EWB 24 months later. By capturing multiple factors relevant to the family environment, more complex relationships among factors could be examined, providing opportunities to identify specific areas of intervention in the effort to maximize a child's EWB and overall HRQoL.

There are some limitations associated with this study. One is the reliance on parent–report data. Because of the age of our sample and the geographic spread of families, self-report from the child was not feasible. A long-term follow-up of the cohort has since been conducted; however, that includes self-report from patients as adolescents or young adults. A possible issue of parental report is the potential for parental depressive symptoms to influence the reporting of their child's HRQoL and in turn EWB. Despite the relatively large proportion of parents with depressive symptoms, we do not believe this was likely to have influenced the reporting of EWB. A previously reported analysis using the HERQULES dataset found that maternal depressive symptoms had a small influence on parents' reporting on items related to energy or fatigue but did not influence reporting on other areas of HRQoL.[39] In our study we used QOLCE-55, which does not contain items on energy or fatigue, and as such the influence of parental depressive symptoms should not be an issue. Parental anxiety could also affect parental reporting, but we are unable to comment on the extent to which our sample of parents was experiencing anxiety symptoms during our study.

Our study employed the QOLCE-55 emotional functioning subscale rather than a stand-alone measure of EWB. The QOLCE-55 subscale for EWB has not undergone extensive validation, particularly testing convergent validity, in comparison to other measures such as the Child Behavior Checklist, a widely used measure of emotional and behavioral problems. However, in the development of the QOLCE-55, internal consistency reliability for the emotional well-being subscale, as measured by Cronbach's alpha, was found to be acceptable ($\rho = 0.88$). Convergent validity was supported by the correlation between the Child Health Questionnaire (CHQ) psychosocial subscale and the QOLCE-55 emotional subscale (Spearman rho = 0.70), and divergent validity was supported by the smaller correlation between the CHQ physical subscale and the QOLCE-55 emotional subscale (Spearman rho = 0.30).[21]

Although use of a fully validated standalone measure may be considered ideal, we believe the EWB domain of the QOLCE-55 is an acceptable measure in terms of its measurement properties and its consistency with conceiving EWB as a broad measure of emotional functioning to encompass a complete state of well-being.

Our sample contains a large range of epilepsy types, number of AEDs taken, and other symptoms of epilepsy; however, it is composed of a relatively large proportion of children with mild epilepsy. This may limit opportunities to observe some effects of epilepsy factors on EWB that may only manifest in children with more severe epilepsy. As well, our sample is of children with newly diagnosed epilepsy and may not be generalizable to all cases of epilepsy.

Finally, the assessment of behavioral and cognitive problems was based on neurologists' subjective ratings rather than use of a formal diagnosis or validated measure.

Future research could build on the findings of this study by examining additional components of the family environment and assessing groups of children with more severe epilepsy. Further elucidation of the mechanisms through which family factors and clinical factors affect EWB would be beneficial in understanding the role of the family. To our knowledge, this study is the first to comprehensively examine the relationship among clinical factors, family factors, and EWB in children with newly diagnosed epilepsy. The family environment appears to be an important component in the treatment of childhood epilepsy and its associated issues. We suggest that clinicians take a family centered care approach when planning a treatment program for a child with epilepsy at diagnosis, taking into account the child's clinical factors, family environment, and any other comorbidities that may lead to a reduction in EWB. Family centered care is a clinical approach to treatment wherein treatment strategies are examined in the context of the family, and inclusion of the family in this approach has been shown to improve parental well-being and increased coping. Because parents are the primary advocates of the health of a child with epilepsy, we expect that taking a family centered care approach would strengthen the family and in turn reduce the impact of epilepsy on a child's EWB.

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DISCLOSURE

None of the authors has any conflict of interest to disclose. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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