



Epilepsy and Parent Stress: The Chicken and the Egg Dilemma

Parent and Family Stress Factors Predict Health-Related Quality in Pediatric Patients With New-Onset Epilepsy.

Wu, YP, Follansbee-Junger, K, Rausch, J, Modi, A. *Epilepsia* 2014;55:866–877.

OBJECTIVE: To examine the influence of parent and family general and epilepsy-related stress on longitudinal generic and epilepsy-specific health-related quality of life (HRQOL) for children with new-onset epilepsy, while controlling for demographic characteristics, disease factors, and antiepileptic drug (AED) adherence. **METHODS:** This prospective, longitudinal study included 124 children with new-onset epilepsy (mean age 7.2 years, standard deviation [SD] 2.9 years). Parents completed questionnaires on parenting stress, perceived stigma, fears and concerns, and HRQOL at 1, 13, and 25 months after diagnosis. Adherence to AEDs was assessed using electronic monitors. A medical chart review was conducted at each visit to obtain seizure and side effect data. **RESULTS:** Higher levels of general and epilepsy-specific parent and family stress, fears and concerns, and perceived stigma negatively affected child generic and epilepsy-specific HRQOL, above and beyond disease and demographic factors. General parenting and family stress affected child generic and epilepsy-specific HRQOL more in the first year of disease management than at 2 years after diagnosis. Higher fears and concerns predicted higher epilepsy-specific HRQOL at 13 months post diagnosis, whereas 2 years post diagnosis, higher fears and concerns predicted lower epilepsy-specific HRQOL. Several demographic (i.e., age) and disease-related variables (i.e., side effects and AED adherence) influenced child generic and epilepsy-specific HRQOL. Although some findings were consistent across generic and epilepsy-specific HRQOL measures, others were unique. **SIGNIFICANCE:** Modifiable parent factors (i.e., general and disease-specific parent and family stress, perceived stigma) impact HRQOL for children with new-onset epilepsy differently over the first 2 years post diagnosis. Psychosocial interventions to improve HRQOL within the first year post diagnosis should address parenting and family stress, overall coping, and anticipatory guidance on managing epilepsy. Interventions targeting adherence, perceived stigma, and fears and concerns could improve HRQOL. Promoting parent management of stress, fears/concerns, and perceived stigma may lead to improved child HRQOL outcomes.

Commentary

As demonstrated in Wu et al.'s well-designed study and in prior studies (See review in [1]), onset of epilepsy in children is a major stressor that impacts parenting, family function, fears and concerns for the future, as well as perceived stigma. Wu et al. and other authors (2) underscore the need for psychosocial intervention to improve parent coping and management of the complex impact of stress due to the onset of epilepsy in children. However, the prediction by baseline high parent fear and concerns of improved 2-year follow-up parent reported child generic and epilepsy specific quality of life (QOL) in Wu et al. implies that intervention might not be necessary. Their findings, therefore, raise several service-related important questions and the need to determine who is in need of treat-

ment, what are the treatment goals, and how best to achieve these goals.

To determine if all or selected parents are in need of intervention, it is important to consider what we have learned from three main areas of research. These include studies on depression, anxiety, coping, and family function in parents of children with epilepsy (1,3), studies on parent- versus child-rated QOL (4), and studies on the two-way relationship between parent depression and child behavior problems (1).

About one-third of mothers of children with new onset and chronic epilepsy have depression (3), a disorder that impacts the ability to deal with stress, parenting, and coping with the demands of running a family. Depressive symptoms in mothers of children with epilepsy are cross-sectionally and prospectively related to mothers' reports of poor child QOL, a relationship that is partially mediated by family functioning and demands (5). The two-way relationship between maternal depression and child behavior problems in children without epilepsy (6) is also found in new onset and chronic pediatric epilepsy (1, 3). Furthermore, maternal depression (7) and



reports of poor child QOL (8) are associated with cognitive and learning problems in children with epilepsy.

Other than one study on maternal anxiety and child QOL in a large sample of mothers of children with epilepsy (9), studies have not been conducted on maternal anxiety and child QOL in pediatric epilepsy. This gap in the literature is important because of the difficulties anxious mothers have dealing with stress, parenting, coping, child behavior problems and learning difficulties, as well as family functioning (10). This is particularly apparent when anxious mothers have children who have a chronic illness with unpredictable seizures. In addition, anxiety is often comorbid with depression (11), which further negatively impacts perceived stress, fears, coping, parenting, management of a family, and report of child QOL in mothers of children with epilepsy.

From the methodological perspective, Wu et al. did not determine the effect of maternal depression, anxiety, and combined anxiety and depression, as well as child behavior and cognitive/learning problems on their findings. The mothers in the study provided the child QOL ratings. Given the known effects of undiagnosed depression or anxiety on stress, fears, worries, and perceived stigma, the study's QOL outcome variables, as well as the ratings of parenting stress, perceived stigma, and fears and concerns—the study's independent variables—might have influenced the parents' QOL ratings.

In terms of the chicken and the egg dilemma, parent stress might reflect parent depression or anxiety, child behavior and learning problems, and family dysfunction above and beyond direct epilepsy effects. Therefore, early identification and treatment of depressive and anxious symptoms in the mothers of children with new onset epilepsy and of behavior and learning problems in their children can have a positive effect on the outcome of epilepsy for these children and their families. A randomized controlled trial comparing cognitive behavior therapy (CBT) and pharmacotherapy with serotonin reuptake inhibitor (SSRI) in mothers who meet criteria for clinical and subclinical depression and anxiety disorders could have both important short- and long-term effects on child behavior, academic achievement, parenting, and family functioning.

Since mothers are usually the primary caretakers, only a few studies have been conducted on fathers of children with epilepsy. The acute response of both parents to a diagnosis of epilepsy decreases with time in fathers and less so in mothers (3, 12). But we also know little of how the two-thirds of mothers of children with epilepsy who are not depressed fare over time and how this is related to their children's QOL. Pfäfflin et al. (13) recently demonstrated improved knowledge, adaptation, epilepsy-related anxiety, and seizure management in parents of children with epilepsy who underwent a group educational program compared to a waitlist control group. Future randomized controlled trials should also examine the short- and long-term efficacy of psychoeducation and bibliotherapy about epilepsy and its comorbidities in fathers and in mothers without evidence for depression or anxiety on parenting, family functioning, and child behavior.

Despite marked advances in studies on the biological and psychosocial aspects of the comorbidities of epilepsy, the ap-

proach used in most studies continues to address the chicken and the egg dilemma. More specifically, many studies have examined the role of seizure variables (frequency, control, syndrome, antiepileptic drugs, age of onset, duration of illness) on the psychiatric, cognitive/linguistic, and social comorbidities and on psychosocial issues, such as parenting, coping, family functioning, parent stress, and QOL. Rather than the chicken-egg approach, an integrative multifactorial biopsychosocial approach is essential to move the field forward and elucidate the impact of epilepsy on parents and children with epilepsy, as well as screen for and treat vulnerable parents and their children.

by Rochelle Caplan, MD

References

1. Austin JK, Caplan R. Behavioral and psychiatric comorbidities in pediatric epilepsy: Toward an integrative model. *Epilepsia* 2007;48:1639–1651.
2. Rodenburg R, Wagner JL, Austin JK, Kerr M, Dunn DW. Psychosocial issues for children with epilepsy. *Epilepsy Behav* 2011;22:47–54.
3. Ferro M, Speechley KN. Depressive symptoms among mothers of children with epilepsy: A review of prevalence, associated factors, and impact on children. *Epilepsia* 2009;50:2344–2354.
4. Baca C, Vickrey BG, Caplan R, Vassar D, Berg AT. Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. *Pediatrics* 2011;128:1532–1543.
5. Ferro MA, Avison WR, Karen Campbell M, 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;52:316–325.
6. Barbot B, Crossman E, Hunter SR, Grigorenko EL, Luthar SS. Reciprocal influences between maternal parenting and child adjustment in a high-risk population: A 5-year cross-lagged analysis of bidirectional effects. *Am J Orthopsychiatry* 2014;84:567–580.
7. Ferro MA, Camfield CS, Levin SD, Smith ML, Wiebe S, Zou G, Speechley KN. Trajectories of health-related quality of life in children with epilepsy: A cohort study. *Epilepsia* 2013;54:1889–1897.
8. Speechley K, Ferro MA, Camfield CS, Huang W, Levin SD, Smith ML, Wiebe S, Zou G. Quality of life in children with new-onset epilepsy: A 2-year prospective cohort study. *Neurology* 2012;79:1548–1555.
9. Williams J, Steel C, Sharp GB, DelosReyes E, Phillips T, Bates S, Lange B, Griebel ML. Parental anxiety and quality of life in children with epilepsy. *Epilepsy Behav* 2003;4:483–486.
10. Affrunti N, Ginsburg GS. Exploring parental predictors of child anxiety: The mediating role of child interpretation bias. *Child Youth Care Forum* 2012;41:517–527.
11. Hunt C, Slade T, Andrews G. Generalized anxiety disorder and major depressive disorder comorbidity in the national survey of mental health and well-being. *Depress Anxiety* 2004;20:23–31.
12. Ramaglia G, Romeo A, Viri M, Lodi M, Sacchi S, Cioffi G. Impact of idiopathic epilepsy on mothers and fathers: Strain, burden of care, worries and perception of vulnerability. *Epilepsia* 2007;48:1810–1814.
13. Pfäfflin M, Petermann F, Rau J, May TW. The psychoeducational program for children with epilepsy and their parents (FAMOSEs): Results of a controlled pilot study and a survey of parent satisfaction over a five-year period. *Epilepsy Behav* 2012;25:11–16.