

Parental quality of life 10 years after their child's epilepsy diagnosis

Background: Although the long-term course of childhood epilepsy is favorable in terms of seizure control, patients often face debilitating cognitive and psychosocial deficits that persist even after seizure remission. Pediatric epilepsy also has a large impact on the family and has been shown to be associated with diminished quality of life (QOL) among parents. However, the long-term outcome of parental QOL is unknown. This study aimed to 1) evaluate parental QOL 10 years after their child was diagnosed with epilepsy and 2) identify epilepsy-, child- and family-related characteristics associated with diminished parental QOL.

Methods: Data were derived from the Health-Related Quality of Life in Children with Epilepsy Study (HERQULES), a large multicenter prospective cohort study of children with newly diagnosed epilepsy. Ten years after baseline evaluation, parental QOL was measured using the Short-Form Health Survey (SF-12-v2), a standardized, validated self-reported questionnaire. Parents also reported on multiple epilepsy-, child- and family characteristics at baseline and 10-year follow-up.

Preliminary results: Data collection was recently completed; 173 parents completed questionnaires. Parental QOL will be compared with normative data and predictors of QOL will be evaluated.

Discussion & Conclusion: It is widely recognized that the burden of epilepsy goes far beyond seizures. This study will identify the long-term impact of epilepsy on parental QOL and identify factors that diminish parental QOL in the long-term.

Interdisciplinary Reflection: Epilepsy requires an interdisciplinary team managing seizures, the child's comorbidities and family functioning. The present study elucidates the importance of an inter-professional, family centered approach to childhood epilepsy.