Children's perspective of quality of life in epilepsy

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ABSTRACT

Objective: To study child mental health, parental support, and social support of children with epilepsy as these relate to quality of life (QOL) using child self-report, seizure-related variables, and estimated verbal intelligence based on receptive vocabulary.

Methods: A cross-sectional structural equation model of baseline data from the QUALITÉ cohort study, which includes 6 Canadian child epilepsy ambulatory programs. A sample of 3,481 children were screened for the following eligibility: 8 to 14 years of age, with active or medication-managed epilepsy. Of 894 eligible children, 506 agreed to participate, of whom 26 were then excluded because of an inability to self-report based on a standard cutoff score of receptive vocabulary lower than 70. The primary outcome of child-reported QOL was measured using the Child Epilepsy QOL Questionnaire.

Results: From the child's perspective, epilepsy-specific QOL is strongly related to their mental health and social support but not to their seizures. Specifically, child mental health and peer support exhibit direct associations with QOL; parental support has both direct and indirect associations with QOL (via child mental health); estimated verbal intelligence exerts its strongest association with QOL through mental health; and seizure status exhibits a weak relationship to QOL only through mental health.

Conclusions: Among children with epilepsy aged 8 to 14 years, mental health and social support should be areas of focus in the assessment of QOL. Controlling seizures is insufficient care for influencing the child's perception of their life. *Neurology*® 2015;84:1830-1837

GLOSSARY

AED = antiepileptic drug; **CFI** = comparative fit index; **CI** = confidence interval; **QOL** = quality of life; **RMSEA** = root-mean-square error of approximation; **SRMR** = standardized root-mean-square residual; **TLI** = Tucker-Lewis Index.

Epilepsy is a complex disorder^{1,2} that can have an impact on all aspects of children's health and quality of life (QOL). Factors affecting QOL, such as seizures, antiepileptic drugs (AEDs), cognitive impairment, and psychological and social domains, have been explored without conclusive evidence about which ones contribute most to child QOL.^{3,4}

Explaining what variables are important to children's QOL is premature without first considering who should be the most suitable agents for making such an appraisal. Recent reviews of QOL measures found that only half of the available child epilepsy-specific measures provided options for child self-report,⁵ and use of child report of QOL was not dominant in child health services research in general.⁶ A dependence on parental report to assess child QOL represents a limitation for both substantive and empirical reasons. The World Health Organization defines QOL as "an individual's perception of [his/her] position in life ... in relation to their goals, expectations, standards and concerns."⁷ This implies that a first-person account from children is needed to assess their QOL and is consistent with a human rights perspective.⁸ In addition,

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Supplemental data
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Table 1 Measures and latent variables

Measured or latent variable	Measure	Early scale validation
Seizure status (measured variable)	No. of AED failures + neurotoxicity (log) + recovery time after seizure + no. of AEDs at present	Not applicable
Verbal intelligence (measured variable)	Peabody Picture Vocabulary Test-III	The sample norming version III was obtained in 1995 and 1996 on an American national sample stratified for various characteristics including various learning abilities. The purpose of this test is to assess verbal ability, receptive vocabulary knowledge, and comprehension of spoken English
Mental health latent variable (overall mood)	KIDSCREEN Mood subscale, 7 items	Content generated with qualitative interviews and focus groups among healthy children and children with chronic conditions over 10 European countries among 3,988 children and 2,526 parents
Mental health latent variable (depression)	Children's Depression Inventory, 10 items	The questionnaire is a symptom-oriented screen of depression in children and adolescents with content based on the adult Beck Depression Inventory. It has been normed with 1,266 public school students aged 7–16 y
Mental health latent variable (anxiety)	Multidimensional Anxiety Scale for Children, 10 items	Scale of anxiety symptomatology including physical symptoms, harm avoidance, social anxiety, and separation/panic. It has been validated on 374 general sample of children 8–17 y and based on previous self-report anxiety scales and expert sorting and selection
Mental health latent variable (attention)	Attention (from NLSCY/BCFPI), 7 items	The scales are based on Diagnostic Interview Schedule for Children, originally validated in the Ontario Child Health Study (including parent and teacher reports of 1,751 population-sampled and 1,027 mental health clinic-sampled children), then the Canadian National Longitudinal Study of Children and Youth. The scales were later adapted in the Brief Child Family Parent Interview (a mental health screening survey for child mental health)
Mental health latent variable (maladaptive conduct)	Conduct (from NLSCY/BCFPI), 6 items	
Mental health latent variable (adaptive conduct)	Cooperativeness (from NLSCY/BCFPI), 6 items	
Parental support latent variable	KIDSCREEN Home subscale, 6 items	Content generated with qualitative interviews and focus groups among healthy children and children with chronic conditions over 10 European countries among 3,988 children and 2,526 parents
Peer support and attitudes latent variable	Harter Social Support Scale (Classmate), 6 items	Content developed based on social construction theories that taps the extent to which one's classmates like them, are friendly, don't make fun of them, listen to what they say, and ask them to join in play or games. Early validation sample included 1,137 public school children in grades 3–8
Epilepsy-specific QOL latent variable	CHEQOL Questionnaire, 25 items	Content developed from qualitative interviews with children with epilepsy; includes Intrapersonal, Secrecy, Intrapersonal, Present Worries, and Normality, validated using 381 Canadian children with epilepsy aged 6–15 y

Abbreviations: AED = antiepilepsy drug; BCFPI = Brief Child and Family Phone Interview; CHEQOL = Child Epilepsy Quality of Life; NLSCY = National Longitudinal Survey of Children and Youth; QOL = quality of life.

numerous reviews and studies report caregiver–child discrepancies in QOL scores.^{9–13} Before asking which variables best explain or predict QOL, we need first to ask children.

Studies that have consulted children have yielded mixed results about the importance of seizure and psychological and social variables to QOL.^{14–18} For example, school-aged children have reported poorer QOL outcomes linked to seizures^{14,15} when mental health or social support were omitted from the predictors of such studies. The studies that have used a child-report approach and included seizure, mental health, and social support^{16,19} have linked the importance of parental support to QOL.¹⁸ However, these studies have not simultaneously accounted for the relative contribution of seizure, psychological, and social influences on QOL. A large evidence gap exists in our understanding of

children's self-reported QOL and the factors that influence it.^{3,4}

Finally, a conceptual framework is needed to adequately study QOL in childhood epilepsy. The Lach et al.³ and Ronen et al.⁴ frameworks posit determinants of QOL, which include the community, the child, and the characteristics of epilepsy and comorbidities. This framework has provided a conceptual basis needed for testing, replicating, and verifying QOL research.

In response to the challenges described above, this study uses exclusive child self-report to assess mental health, peer support, parental support, and QOL; incorporates seizure status and an estimate of verbal intelligence in the assessment of QOL; and uses a conceptual framework to inform hypotheses about the factors influencing QOL, while studying the simultaneous relative contribution of each factor.

Figure 1 Revised Ronen et al.⁴ a priori conceptual model of quality of life (QOL)

Revised from Ronen et al. © 2003; licensee BioMed Central Ltd. This is an Open Access article, available at: <http://www.hqlo.com/content/1/1/36>.

METHODS Standard protocol approvals, registrations, and patient consents.

The participants in this study were recruited from 6 Canadian child epilepsy tertiary care ambulatory programs. The details of ethics, recruitment, and study procedures were outlined in an earlier report.²⁰ Ethics approval was granted by the hospital research ethics boards of each of the participating programs; informed consent was obtained from all caregivers and child assent was obtained when appropriate. We sought to achieve an inclusive sample of children with active or medication-managed epilepsy. Inclusion criteria were as follows: ages 8 to 14 years at the time of enrollment, ability to report in English or French, seizures in the previous 12 months, or on medication to control seizures. Children who had a standard score below 70 on the Peabody Picture Vocabulary Test–Third Edition were excluded from this self-report study.

Demographic and health information. Caregivers provided demographic information and, in conjunction with chart abstraction and clinical interview, information on epilepsy and related health indicators. At the time of the initial visit, we obtained information on seizure status, including the number of antiseizure medications, the number of failed antiseizure medications, Neurotoxicity Rating Scale score, and the functional recovery time of a seizure.

Child self-report questionnaires. This study used reliable and valid child self-report measures psychometrically assessed among children with epilepsy.²⁰ The main outcome was QOL, measured using the Child Epilepsy QOL Questionnaire,²¹ developed for children with epilepsy and subsequently validated in multiple studies and languages.^{21–25} The questionnaire has 25 items and includes the epilepsy-specific QOL domains of Intrapersonal, Secrecy, Interpersonal, Present Worries, and Normality.²¹

To measure child mental health, we used standardized scales that assessed both externalizing problems (attention problems, oppositional behavior, and conduct problems) and internalizing

problems (mood and anxiety). Overall mood was measured with the KIDSCREEN 7-item child report General Mood subscale^{26,27}; depression was measured using the Children's Depression Inventory (CDI) 10-item short form; anxiety was measured using the Multidimensional Anxiety Scale for Children 10 instrument²⁸; and measures of inattention, conduct, and cooperativeness were taken from the Statistics Canada National Longitudinal Study of Children and Youth, Canadian population health survey.²⁹

Parental support was measured using the KIDSCREEN 6-item child report Home subscale.^{26,27} General peer support was measured using the Classmate subscale of the Harter³⁰ Social Support Scale for Children, child and adolescent versions. All child self-report measures were scored positively such that a higher score represented more of the desirable trait. A summary of the variables included in the model and the latent factors represented is shown in table 1.

Analysis. Conceptual model. The conceptual framework tested in this study was based on an epilepsy-specific representation of child QOL as published by Ronen et al.⁴ and later Lach et al.³ The frameworks posited that epilepsy and comorbidity factors were predictors of QOL, with child, family, and community characteristics as potential mediators or moderators of that relationship. Further empirical testing by Ronen et al.¹⁸ showed that child (mental health), family (parent support), and community (peer support) factors exhibited independent effects on QOL.

A revised version of the Ronen et al.⁴ and Lach et al.³ frameworks presented here identifies parental and peer support as independent predictors of QOL (figure 1). Thus, the *direct* relationships of epilepsy, comorbidity, child, family, and community factors with QOL were tested. The posited mediated relationship between parental support, peer support, cognition, and seizures and QOL through the child's mental health was also tested. The conceptual grouping of the factors potentially related to QOL remains unchanged from the original model.

Table 2 Child characteristics

Characteristic	N (%)
Sex	
Male	248 (51.7)
Female	232 (48.3)
How recent was the last seizure?	
Active last 12 mo	275 (57.3)
Active last 24 mo	83 (17.3)
Inactive for 24 mo or longer but taking AED	91 (19.0)
Missing	31 (6.45)
No. of seizure types	
1	316 (65.8)
2	120 (25.0)
≥3	36 (7.5)
Missing	8 (1.7)
Seizure types at baseline^a	
Simple partial	78
Complex partial	183
Generalized tonic clonic	176
Absence	150
Myoclonic	22
Other	30
Comorbid neurologic conditions (e.g., CP, autism)	
Yes	112 (23.3)
None	368 (76.7)
Seizure severity in past 12 mo	
None	142 (29.6)
Low	153 (31.9)
High	177 (36.9)
Missing	8 (1.7)
Stream of education	
All regular	322 (67.1)
Partial	132 (27.5)
All modified	24 (5.0)
Missing	2 (0.4)
No. of AEDs	
0	27 (5.6)
1	344 (71.7)
2	82 (17.7)
≥3	20 (4.2)
Missing	7 (1.5)

Abbreviations: AED = antiepileptic drug; CP = cerebral palsy.

^aChildren might have more than one type of seizure.

Structural equation model. We used a structural equation modeling approach to determine the relative contributions (direct or indirect) of seizure, estimated verbal intelligence, child mental health, and social factors to each other and to QOL, and to

understand the extent of measurement error in the constructs observed. Structural equation modeling involves a series of detailed specific steps described elsewhere.³¹ Briefly, there are 2 general phases in testing this structural equation modeling: the first is to construct and test the *measurement* model, which provides information about measurement error leading to unreliability; the second is the *structural* stage, which tests the a priori–specified paths between the variables hypothesized to influence child QOL.

The analysis was conducted with SPSS version 20 (IBM Corp., Armonk, NY) and *Mplus* version 7.1 (Muthén & Muthén, Los Angeles, CA) software using the maximum likelihood method to estimate parameters and standard errors by using Satorra-Bentler χ^2 , a function that is robust to nonnormality for dependent and independent variable data. Fit of the measurement and structural model was assessed with goodness-of-fit statistics using prespecified cutoffs: $\chi^2/df < 2$, Tucker-Lewis Index (TLI) > 0.9 , standardized root-mean-square residual (SRMR) 0.08, comparative fit index (CFI) > 0.9 , and root-mean-square error of approximation (RMSEA) < 0.04 using a 90% confidence interval (CI). Little's test and pattern recognition were used to verify the randomness of missing data. Each variable was individually checked for the percent missing. Variables with $> 5\%$ missing data were assessed using between-groups significance testing for all demographic, seizure, mental health, and social support variables. A stepwise regression function created 5 datasets for the missing predictor variables using chained equations imputation algorithm in SPSS.

Measurement model. Latent variables were created for child mental health, parental support, and peer support, whereby items were specified to load onto their measure of origin using confirmatory factor analysis. A latent variable was similarly constructed for our outcome of interest, QOL, where subscale scores were used as the measured variables loading on the latent variable.

Lagrange multipliers and residual correlations were used to assess potential improvements to model fit. Correlating residuals from items or subscales was permitted only when there was a strong conceptual rationale for doing so. Cross-loading between items and another latent variable was not permitted. Standardized residuals were checked for significance at $p < 0.01$.

Structural model. Verbal intelligence and seizure status were included in the structural model as measured variables. Verbal intelligence was measured by standard z scores on the Peabody Picture Vocabulary Test measure while seizure status was measured as a sum score of seizure and seizure-related indicators including number of AEDs, AED failures, neurotoxicity score, and seizure recovery time (see table e-1 on the *Neurology*® Web site at Neurology.org). The model was evaluated based on the strength and significance of paths between measured and latent variables as well as goodness of fit described above.

RESULTS Of the 3,481 families screened, 894 were eligible for the study and 506 agreed to participate, of whom 26 children did not meet verbal IQ cutoff scores or were unable to be assessed for IQ secondary to physical, communication, or cognitive impairment. This left 480 cases. The average mean age of included children was 11.41 years, SD = 2.10. Child and family descriptive characteristics are reported in tables 2 and 3. Study data for each child were collected within an average of 8.2 months, SD = 2.86.

Data were deemed missing completely at random and less than 5% of each individual variable was missing, except for social support. Social support was

Table 3 Family characteristics

	No. (%)
Total household income/y	
<\$10,000	7 (1.5)
\$10,000–\$20,000	19 (4.0)
\$20,000–\$30,000	17 (3.5)
\$30,000–\$40,000	33 (6.9)
\$40,000–\$50,000	46 (9.6)
\$50,000–\$60,000	47 (9.8)
≥\$60,000	297 (61.9)
Undisclosed	13 (2.7)
Missing	1 (0.2)
Family structure	
Single parent	41 (8.5)
Nuclear family	358 (74.6)
Separated/divorced	39 (8.1)
Reconstituted	38 (7.9)
Extended family	1 (0.2)
Foster family	2 (0.4)
Missing	1 (0.2)
Receiving social assistance	
Yes	24 (5.0)
No	455 (94.8)
Missing	1 (0.2)
Highest maternal educational attainment	
Did not complete high school	26 (5.4)
High school	118 (24.6)
College or university	325 (67.6)
Not applicable	10 (2.1)
Missing	1 (0.2)
Primary language spoken at home	
English	360 (75.0)
French	95 (19.8)
Other	24 (5.0)
Missing	1 (0.2)

missing less than 15% at random according to pattern recognition and between-groups significance testing for demographic, health, and self-report variables.

Measurement model. The internal consistencies of the measures were as follows: Child Epilepsy QOL Questionnaire = 0.75; KIDSCREEN General Mood subscale = 0.86; Children's Depression Inventory–10 = 0.78; Externalizing Inattention subscale = 0.84, Conduct subscale = 0.81, Cooperativeness subscale = 0.83; KIDSCREEN Home subscale = 0.78; and Social Support Scale for Children, Classmate subscale = 0.74. The anxiety measure Multidimensional Anxiety Scale

for Children 10 demonstrated reliability that was too low to carry forward into the measurement model: the interitem correlation range was 0.09 to 0.43, interitem correlation mean was 0.19, SD = 0.07, and internal consistency was 0.70.

The latent variable “child mental health” retained the measured variables of overall mood, depression, attention, conduct, and cooperation using a bifactor solution, used because the average factor loadings were higher for the general factor than for specific mental health measures.³² Factor loadings on all but 2 questionnaire items were significant (table e-2).

The peer and parental support latent variables were formed by splitting each measure in half to provide parallel forms, and all factor loadings were significant (table e-3).³¹ Seven pairs of item residuals were specified to correlate to improve model fit (table e-4). Goodness-of-fit statistics were satisfactory: TLI = 0.92, CFI = 0.91, SRMR = 0.05, and RMSEA = 0.029 (CI 0.026–0.032), and χ^2 (1,052) = 1,496.05, χ^2/df = 1.42. An abbreviated representation of the final measurement model is shown in figure e-1.

Structural model. The final structural model (figure 2) shows the strength and significance of all paths using standardized coefficients; this can be interpreted similarly to individual correlation coefficients when all the other factors in the model are held constant. For example, child mental health is directly and positively related to QOL with the strength of 0.27 when seizure status, estimated verbal IQ, and parental and peer support are held constant.

The total variance explained in child mental health and QOL were 0.33 and 0.45, respectively. The direct, indirect, and total effect of each predictor with QOL allows for comparison of model paths (table e-5). Child mental health, parental support, and peer support showed strong total effects to QOL. Parental support demonstrated an indirect relationship to QOL via the child's mental health. Overall model fit was good: χ^2 (970) = 1,467.82, χ^2/df = 1.51, p < 0.01, TLI = 0.91, CFI = 0.90, RMSEA = 0.033 (CI 0.029–0.036), and SRMR = 0.05.

DISCUSSION This work is novel because it relies on child self-report and includes measures of seizures, estimated intelligence, mental health, and social variables to explain QOL. From the perspective of 8- to 14-year-old children, QOL is not related to seizure severity but is associated with mental health and peer and parental support. This finding mirrors literature reviews showing that repeated positive daily experiences (such as in the family or at school) are more important to children's perceived life satisfaction than 1 or 2 major life stressors (such as the diagnosis of

Figure 2 Final structural equation modeling of child-reported QOL showing standardized coefficients

Higher scores in IQ, Mental Health, Peer Support, Parental Support, and quality of life (QOL) are indicative of positive traits, while a higher score in seizure status is more indicative of severity or problem.

epilepsy).^{33,34} In contrast, caregiver-proxy reports of children's QOL highlight the importance of cognition and seizure factors.^{35–37} This tension between how parents and children perceive factors that influence QOL does not invalidate the perspective of caregivers but underscores the importance of obtaining the perspectives of children. There is thus potential for clinicians and service providers to improve or maintain children's positive perceptions of their lives in the context of an epilepsy diagnosis through the application of psychosocial care.³⁸

The strong direct relationship between peer support and QOL implies that interventions geared toward peers could have an immediate and palpable effect on child QOL. Interventions that do precisely this have been offered by community groups³⁸ and have demonstrated effectiveness³⁹; however, referrals to such programs might be underused by epilepsy clinical programs.

The importance of peers to QOL was an expected finding from the children's perspective; however, they reported that parents were almost as important, albeit in a more nuanced way. The indirect relationship between parental support and QOL, as linked via children's mental health, has 2 possible implications: children who enjoy good mental health have better perceptions of their parents and/or elicit more supportive parenting, *or* supportive parenting leads to better child mental health outcomes. This relationship is likely complex and bidirectional.⁴⁰ Regardless, parental support should be explored further as a target for intervention on the grounds of the demonstrated

importance both to children's mental health and QOL. Longitudinal approaches should be used to determine precursors and consequences, and to infer causal links between parenting and child mental health with QOL. More specific study of the mechanisms behind adaptive parenting and child mental health and QOL would also be useful for clinical purposes.

The 8 to 14 years age range of study participants represents the views of middle to late childhood and early adolescence. The sample represented here came from a tertiary care center and these children were likely to have the best seizure management available to them. The lack of importance of seizures to QOL should be interpreted in this context. Readers should exercise caution applying this model to early childhood, young adulthood, children who are unable to self-report, and children who do not have access to specialized neurology care. Seizures and comorbidity were included as measured variables in this model and as a result, the strength of their relationship with other factors might be slightly underestimated relative to latent variables. Studies under way by our group will build on this research by determining the parents' perspectives on their child's QOL; by doing so, we will attempt to reconcile or explain agreements and discrepancies between parent and child perspectives. We will also incorporate longitudinal trajectory-based models of both parent and child factors that might be associated with QOL among children with epilepsy. Finally, we plan to explore more specific information about the characteristics that distinguish subgroups so that clinicians can identify children most at risk for QOL problems.

AUTHOR CONTRIBUTIONS

Michael Boyle: QUALITÉ coinvestigator, manuscript review, and input to the analysis. Charles Cunningham: QUALITÉ project design, study management, review of analysis, manuscript editing, and final approval. Aileen Davis: overall study rationale, oversight of analysis and review of analysis, manuscript review, and final approval. Nora Fayed: conception of specific study, analysis, manuscript writer, and principal author. The statistical analysis was conducted by Nora Fayed. Lucyna Lach: QUALITÉ coinvestigator (conception, grant writing, data collection, and review of manuscript). Peter Rosenbaum: QUALITÉ coinvestigator on all aspects of the study (conception, grant writing, execution, analysis, and writing). David L. Streiner: QUALITÉ coinvestigator on all aspects of the study (conception, grant writing, execution, analysis, and writing). Gabriel M. Ronen: principal investigator of the QUALITÉ project and grant; involved in every stage of the conception analysis and interpretation.

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REFERENCES

- Hauser WA. Recent developments in the epidemiology of epilepsy. *Acta Neurol Scand Suppl* 1995;162:17–21.
- Bell GS, Neligan A, Sander JW. An unknown quantity: the worldwide prevalence of epilepsy. *Epilepsia* 2014;55:958–962.
- Lach LM, Ronen GM, Rosenbaum PL, et al. Health-related quality of life in youth with epilepsy: theoretical model for clinicians and researchers: part I: the role of epilepsy and co-morbidity. *Qual Life Res* 2006;15:1161–1171.
- Ronen GM, Streiner DL, Rosenbaum P. Health-related quality of life in childhood epilepsy: moving beyond “seizure control with minimal adverse effects”. *Health Qual Life Outcomes* 2003;1:36.
- Sadeghi S, Fayed N, Ronen GM. Patient-reported outcome measures in pediatric epilepsy: a content analysis using World Health Organization definitions. *Epilepsia* 2014;55:1431–1437.
- Fayed N, De Camargo OK, Kerr E, et al. Generic patient-reported outcomes in child health research: a review of conceptual content using World Health Organization definitions. *Dev Med Child Neurol* 2012;54:1085–1095.
- World Health Organization. WHOQOL User Manual. Geneva: WHO; 1998.
- United Nations. Convention on the Rights of the Child; 1989. <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>. Accessed January 2015.
- Ingerski LM, Modi AC, Hood KK, et al. Health-related quality of life across pediatric chronic conditions. *J Pediatr* 2010;156:639–644.
- Eiser C, Morse R. Can parents rate their child's health-related quality of life? Results of a systematic review. *Qual Life Res* 2001;10:347–357.
- Waters E. Influence of parental gender and self-reported health and illness on parent-reported child health. *Pediatrics* 2000;106:1422.
- Baca CB, Vickrey BG, Hays RD, Vassar SD, Berg AT. Differences in child versus parent reports of the child's health-related quality of life in children with epilepsy and healthy siblings. *Value Health* 2010;13:778–786.
- Verhey LH, Kulik DM, Ronen GM, Rosenbaum P, Lach L, Streiner DL. Quality of life in childhood epilepsy: what is the level of agreement between youth and their parents? *Epilepsy Behav* 2009;14:407–410.
- Montanaro M, Battistella PA, Boniver C, Galeone D. Quality of life in young Italian patients with epilepsy. *Neurol Sci* 2004;25:264–273.
- Benavente-Aguilar I, Morales-Blancuez C, Rubio EA, Rey JM. Quality of life of adolescents suffering from epilepsy living in the community. *J Paediatr Child Health* 2004;40:110–113.
- Eddy C, Rizzo R, Gulisano M, Cali P, Robertson M, Cavanna A. Quality of life in young people with treatment-responsive epilepsy: a controlled study. *Epilepsy Behav* 2010;19:623–626.
- Hirfanoglu T, Serdaroglu A, Cansu A, Soysal AS, Derle E, Gucuyener K. Do knowledge of, perception of, and attitudes toward epilepsy affect the quality of life of Turkish children with epilepsy and their parents? *Epilepsy Behav* 2009;14:71–77.
- Ronen GM, Streiner DL, Verhey LH, et al. Disease characteristics and psychosocial factors: explaining the expression of quality of life in childhood epilepsy. *Epilepsy Behav* 2010;18:88–93.
- Turky A, Beavis JM, Thapar AK, Kerr MP. Psychopathology in children and adolescents with epilepsy: an investigation of predictive variables. *Epilepsy Behav* 2008;12:136–144.
- Ronen GM, Streiner DL, Boyle MH, et al. Outcomes trajectories in children with epilepsy: hypotheses and methodology of a Canadian longitudinal observational study. *Pediatr Neurol* 2014;50:38–48.
- Ronen GM, Streiner DL, Rosenbaum P; Canadian Pediatric Epilepsy Network. Health-related quality of life in children with epilepsy: development and validation of self-report and parent proxy measures. *Epilepsia* 2003;44:598–612.
- Yam WK, Chow SM, Ronen GM. Chinese version of the parent-proxy health-related quality of life measure for children with epilepsy: translation, cross-cultural adaptation, and reliability studies. *Epilepsy Behav* 2005;7:697–707.
- Ronen GM, Rosenbaum P, Law M, Streiner DL. Health-related quality of life in childhood epilepsy: the results of children's participation in identifying the components. *Dev Med Child Neurol* 1999;41:554–559.
- Stevanovic D, Tepavcevic DK, Jovic-Jakubi B, et al. Health-Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25): preliminary data for the Serbian version. *Epilepsy Behav* 2009;16:599–602.
- Brabcova D, Krsek P, Kohout J, Zarubova J. Psychometric properties of the modified Czech version of the children self-report Quality-of-Life Measure for Children with Epilepsy (CHEQOL-25). *Epilepsy Behav* 2014;33:31–38.
- Ravens-Sieberer U, Erhart M, Wille N, Wetzell R, Nickel J, Bullinger M. Generic health-related quality-of-life assessment in children and adolescents: methodological considerations. *Pharmacoeconomics* 2006;24:1199–1220.

27. Ravens-Sieberer U, Gosch A, Rajmil L, et al. KIDSCREEN-52 quality-of-life measure for children and adolescents. *Expert Rev Pharmacoecon Outcomes Res* 2005;5:353–364.
28. March JS, Parker JD, Sullivan K, Stallings P, Conners CK. The Multidimensional Anxiety Scale for Children (MASC): factor structure, reliability, and validity. *J Am Acad Child Adolesc Psychiatry* 1997;36:554–565.
29. Statistics Canada. Microdata User Guide: National Longitudinal Survey of Children and Youth—Cycle 3. 1998–1999. 2001.
30. Harter S. Manual for the Social Support Scale for Children. University of Denver; 1985.
31. Streiner DL. A Guide for the Statistically Perplexed: Selected Readings for Clinical Researchers. Toronto: University of Toronto Press; 2013:198–210.
32. Reise SP. The rediscovery of bifactor measurement models. *Multivariate Behav Res* 2012;47:667–696.
33. Huebner ES, Suldo SM, Smith LC, McKnight CG. Life satisfaction in children and youth: empirical foundations and implications for school psychologists. *Psychol Schools* 2004;41:81–93.
34. Proctor CL, Linley PA, Maltby J. Youth life satisfaction: a review of the literature. *J Happiness Stud* 2009;10:583–630.
35. Sherman E, Slick DJ, Connolly MB, Eyrl KL. ADHD, neurological correlates and health: related quality of life in severe pediatric epilepsy. *Epilepsia* 2007;48:1083–1091.
36. Sherman EM, Slick DJ, Eyrl KL. Executive dysfunction is a significant predictor of poor quality of life in children with epilepsy. *Epilepsia* 2006;47:1936–1942.
37. Connolly AM, Northcott E, Cairns DR, et al. Quality of life of children with benign rolandic epilepsy. *Pediatr Neurol* 2006;35:240–245.
38. England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: promoting health and understanding: a summary of the Institute of Medicine report. *Epilepsy Behav* 2012;25:266–276.
39. Martiniuk A, Speechley K, Secco M, Campbell M, Donner A. Evaluation of an epilepsy education program for grade 5 students: a cluster randomized trial. *Epilepsy Behav* 2007;10:604–610.
40. Powdthavee N, Vignoles A. Mental health of parents and life satisfaction of children: a within-family analysis of intergenerational transmission of well-being. *Soc Indicators Res* 2008;88:397–422.

This Week's *Neurology*® Podcast

Dystonia: Five new things

This podcast begins and closes with Dr. Robert Gross, Editor-in-Chief, briefly discussing highlighted articles from the May 5, 2015, issue of *Neurology*. In the second segment, Dr. Jeff Ratliff talks with Dr. Brian Berman about his paper on five new things about dystonia. Dr. Adam Numis reads the e-Pearl of the week about hereditary hemorrhagic telangiectasia. In the next part of the podcast, Dr. Ted Burns focuses his interview with Dr. Andy Mammen on the topic of immune-mediated necrotizing myopathy.

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