Original article

Epileptic Disord 2010; 12 (4): 275-82

Correlation between child and parental perceptions of health-related quality of life in epilepsy using the PedsQL.v4.0 measurement model

Zulfi Haneef[1,5], Mitzie L. Grant[2,3,4], Ignacio Valencia[3,4,5], Elizabeth F. Hobdell[4], Sanjeev V. Kothare[4,6], Agustin Legido[3,4,5], Divya Khurana[3,4,5]

[1] Department of Neurology, Temple University Hospital
[2] Department of Psychiatry, Drexel University College of Medicine
[3] Department of Pediatrics, Drexel University College of Medicine
[4] Department of Pediatrics, St. Christopher's Hospital for Children
[5] Department of Neurology, Drexel University College of Medicine, Philadelphia, Pennsylvania
[6] Department of Neurology, Children's Hospital, Boston, Massachusetts, USA

Received August 11, 2010; Accepted October 7, 2010

ABSTRACT – Health-related quality-of-life measures in childhood epilepsy are typically limited to a particular functional domain, specific age group, parent proxy-report, or child self-report. Generic health-related quality-of-life instruments in paediatric epilepsy comparing child self-reports with simultaneous parent proxy-reports have not been previously investigated. A previously validated generic questionnaire, the Pediatric Quality of Life version 4 (PedsQL.v4.0), was used to prospectively assess parental and child perceptions of health-related quality of life in 100 children with epilepsy. The correlation between child and parental health-related quality-of-life perceptions across all domains was excellent ($p < 0.001$) and both were significantly lower than those for healthy controls ($p < 0.001$). Parents' perceptions of their children's health-related quality of life were lower than those for other chronic illnesses ($p < 0.001$), especially for refractory epilepsy. The presence of neurological or psychiatric comorbidities also had an adverse impact on health-related quality of life. The PedsQL.v4.0 measures health-related quality of life from both the parent's and child's perspective. Ease of use makes this instrument attractive for routine clinical use.

Key words: childhood epilepsy, paediatric epilepsy, quality of life, HRQOL, PedsQL.v4.0

Correspondence:
D. Khurana
St. Christopher's Hospital for Children,
E. Erie Ave. & N. Front St.,
Philadelphia, PA 19134, USA
<divya.khurana@drexelmed.edu>

doi: 10.1684/epd.2010.0344

Epilepsy is a common disorder with about 100,000 cases identified annually in the United States (Annegers, 1994). Although traditional medical care stresses adequate seizure control with AEDs, it is increasingly recognized that a holistic approach should consider the impact on a patient's quality of life (QOL) (Jacoby, 1992; Norrby *et al.*, 1999). Research has shown that seizure frequency and duration affect QOL (Jacoby *et al.*,

1996; Au *et al.*, 2002). Many non-epilepsy factors also affect QOL for treatment-resistant epilepsy, including medical and psychiatric comorbidity, social factors, and self-esteem (Schachter, 2005). Available measures to evaluate health-related quality of life (HRQOL) in children with epilepsy are limited, with some confined to a particular domain providing a limited HRQOL profile (Batzel *et al.*, 1991; Hoare and Russell, 1995; Gilliam *et al.*, 1997). Some are applicable only to a particular age group such as adolescents (Batzel *et al.*, 1991; Cramer *et al.*, 1999). Others are specific to either parent proxy-reporting (Hoare and Russell, 1995; Carpay *et al.*, 1996; Sabaz *et al.*, 2000; Camfield *et al.*, 2001) or child self-report (Batzel *et al.*, 1991; Cramer *et al.*, 1999). Only two groups have developed epilepsy-specific instruments with both parent proxy and child self-reporting of HRQOL scores (Arunkumar *et al.*, 2000; Ronen *et al.*, 2003).

When the child is too young or cognitively impaired to complete an HRQOL instrument, parent proxy-reporting becomes important. Comparing the child and parental perceptions of HRQOL becomes significant in this context. Few studies have compared child and parental perceptions of HRQOL using readily available standardized instruments. The use of a generic HRQOL instrument in paediatric epilepsy comparing child self-report with simultaneous parent proxy-reporting has not been previously studied. A recent study examined the effects of single seizures and newly diagnosed untreated epilepsy on the parent proxy HRQOL scores using the PedsQL (Pediatric Quality of Life Inventory) measurement model, but child HRQOL scores were not investigated (Modi *et al.*, 2009). The PedsQL.v4.0 (PedsQL, version 4) is a brief, standardized, generic, modular, and multidimensional instrument designed for use in healthy children as well as children with acute and chronic health conditions (Varni *et al.*, 1999). Our study investigated both parental and child self-perceptions of QOL in children with epilepsy using the PedsQL.v4.0 model.

Methods

The study was approved by the Institutional Review Board at Drexel University College of Medicine and was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

Recruitment

This study included children between 2 and 18 years of age with epilepsy diagnosed more than 3 months previously. Epilepsy was defined as the occurrence of two or more unprovoked seizures and was further categorized as refractory or well-controlled. Children with well-controlled epilepsy were those who were seizure-free for at least six months on a single anticonvulsant. Children with refractory epilepsy were those who had at least one seizure per month after three trials of AEDs. The study was performed in a children's hospital serving predominantly families from a socioeconomically disadvantaged inner-city region. In compliance with the hospital's institutional review board, after informed consent and assent were obtained, children and their families attending the neurology clinic between March 2003 and December 2004 completed a brief demographic questionnaire and the PedsQL.v4.0 questionnaire. If the primary caregiver was not the parent, the parent proxy-reporting questionnaire was given to the primary caregiver for completion. For half of the group, a study coordinator read the questionnaires to the parent and child. For the other half, parent and child completed the questionnaires during the office visit. In a few instances, families were permitted to return the questionnaire by mail when time was insufficient to complete it during the office visit.

Information regarding socioeconomic status and duration of diagnosis and medications was collected from the clinic chart. The seizure type, epilepsy syndrome, and other concomitant neurological conditions were diagnosed by the treating physician. Information was abstracted from the chart concerning neurological and psychiatric comorbid conditions (NPCCs) such as attention deficit disorder, learning disabilities, mental retardation, and psychiatric conditions such as depression or aggressive behaviours. Diagnoses were made using *Diagnostic and Statistical Manual-IV* criteria by the treating physician or were pre-existing diagnoses made by psychiatrists whom the family had consulted or who were employed by the child's school district.

Measurements

QOL measure

Age-appropriate versions of the PedsQL were administered to parents of children 2-18 years of age and to children 5-18 years of age. The questionnaires consisted of 23 items covering four generic core scales, each with multiple items (physical: eight items, emotional: five items, social: five items, and school functioning: three items for toddlers/five items for older children). Each item was rated on a scale from 0 to 4 and scored according to the guidelines established by Varni *et al.* (2003). Items were subsequently reverse-scored and linearly transformed to a 0- to 100-point scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0) with higher converted scores indicating a better quality of life.

PedsQL calculates two summary scores from the above measurements. The physical health summary score is the same as the physical functioning subscale (eight items), and the psychosocial health summary score is the mean of the emotional, social, and school functioning subscales (15 items). The total summary score was calculated from the mean of all answered items.

HRQOL scores from the current sample were compared with normative values previously reported by Varni *et al*. (2003) for healthy children (5,079 children, 8,713 parents) and children with chronic illness (574 children, 831 parents) including asthma, attention deficit hyperactivity disorder, depression, and diabetes. This population aged 2-16 years was sampled by mail survey whereas children aged 8-16 years self-administered the questionnaire and parents assisted with administration for younger children.

Socioeconomic status score

A socioeconomic status score was calculated based on the occupational status and educational status of the mother and father using the four-factor index of social status by Hollingshead (1975, unpublished). The occupational status of the parent was scored from 1 to 9 and the educational status was scored from 1 to 7. A retired person was scored as if he or she were still working. The social score was computed from the above variables by a formula that gives a factor weight of 5 for occupation and a factor weight of 3 for education as follows: social status score = [(occupation scale score) × 5] + [(education scale score) × 3]. If both parents were working, the social status score was the average of the individual scores. If only one partner was working, the social status score of the working spouse was taken. The score ranges from 8 to 67 and a higher score reflects a better socioeconomic status.

Data analysis

Data were analyzed using SPSS version 15.0 (Chicago, IL). Pearson's test was performed to examine correlation between HRQOL measures and parental age, age at seizure onset, length of diagnosis, duration of an average seizure, seizure frequency, and the socioeconomic status as reflected by the Hollingshead score. The Kruskal-Wallis test was used to compare the HRQOL measures with the number of NPCCs and the number of AEDs. Mann-Whitney *U* tests examined the association of the individual NPCCs specified earlier and the severity of epilepsy (well-controlled *versus* refractory) with the outcome HRQOL measures. Student *t*-tests were used to look for differences in HRQOL perceptions between boys and girls and to compare the means of the various individual, summary, and total HRQOL scores of our sample with the previously reported means for healthy children and for children with chronic health conditions. The HRQOL scores of children with well-controlled epilepsy with and without NPCCs and children with refractory epilepsy were compared using analysis of variance (ANOVA) and *t*-tests for post hoc analysis. We used GraphPad software (GraphPad Software, Inc., La Jolla, CA) for comparing our population to children with chronic health conditions and healthy children. A significant effect was shown for the method of HRQOL administration (self-report *versus* coordinator-assisted report completion; $p < 0.03$), with coordinator-assisted scores higher across all groups than self-report scores (well-controlled epilepsy with and without NPCCs and children with refractory epilepsy). Results of analysis of covariance (ANCOVA), controlling for method of administration, remained consistent with those obtained from ANOVA.

Results

A total of 106 parent proxy PedsQL.v4.0 questionnaires were administered of which six were incomplete and were excluded. Sixty-seven children completed the self-report PedsQL.v4.0. Nine were too young and 24 were otherwise unable to complete the measure. The demographic variables and seizure characteristics are listed in *table 1*.

NPCCs seen in our patient population included attention deficit hyperactivity disorder (n = 14, 12.7%), learning disability (n = 16, 14.5%), global delay/mental retardation (n = 32, 29.1%), autism (n = 6, 5.5%), motor problems (n = 18, 16.4%), and other psychiatric diagnoses (n = 4, 3.6%). Forty-six children had no NPCCs, 27 had one NPCC, 25 had two, and two had three NPCCs. All children with refractory seizures (n = 20) had NPCCs. The sample with well-controlled epilepsy (n = 80) was subdivided into those with (n = 46) and those without (n = 34) NPCCs.

According to the Hollingshead score described previously, the median score for maternal education was 4, with an interquartile range (IQR) of 4-5, and median score for paternal education was 5 (IQR 4-6). The median maternal as well as paternal occupational scale score was 5 (IQR 4-6). The mean social status score for both parents combined was 35.3 (standard deviation, 12.9).

Correlations of PedsQL.v4.0 data between 67 pairs of parent and child reports were highly significant for total summary scores as well as for the physical health and psychosocial health summary scores and emotional, social, and school functioning subscales ($p < 0.001$), reflecting a high degree of concordance across all domains *(table 4)*. The significant results obtained for the child self-reports and parent proxy-reports are detailed separately below.

Child self-report measure

A descriptive analysis of the PedsQL.v4.0 scores for both child and parent is given in *table 2*, along with comparisons to normative data for groups of healthy controls and children with chronic illness (Varni *et al.*, 2003). Compared with scores from healthy controls, the HRQOL scores in our subjects were significantly lower ($p < 0.001$) across all domains. Compared with the control sample with other chronic health conditions, our

Table 1. Demographics and seizure characteristics.

Demographics (n = 100)	**Child**	**Parent**	**Mother**	**Father**
Age (y)				
- Mean	10.1	39.2	38.6	39.8
- SD	4.2	7.5	7.1	7.9
- Range	2.1-18.8	27-60		
Male gender	59 (50.9%)			
Hollingshead social scores				
- Mean		35.3	36.4	35.5
- SD		12.9	14.0	
- Range		9-66	9-61	9-61
Seizure characteristics	**Child**			
Age at onset (y)				
- Mean ± SD (range)	5.2 ± 4.4 (0-16)			
Duration of epilepsy (y)				
- Mean ± SD (range)	4.8 ± 4.3 (0.3-18.2)			
Median number of medications (range)	2 (1-11)			
Number of hospitalizations in past year				
- Mean ± SD (range)	1.7 ± 3.1 (0-20)			
Seizure severity				
- Well-controlled	80 (80%)			
- Refractory	20 (20%)			
Seizure type				
- Generalised tonic-clonic	21 (20.0%)			
- Absence	13 (12.4%)			
- Complex partial	47 (44.8%)			
- Infantile spasm	1 (1.0%)			
- Mixed/Lennox-Gastaut	16 (15.2%)			
- Other	7 (6.7%)			

Table 2. PedsQL scores for children with well-controlled epilepsy, chronic illnesses, and healthy controls.

	Child self-report		
	Epilepsy (n = 67)	**Healthy control (n ~5,070)**	**Chronic illness (n ~573)**
Emotional	64.9 ± 25.7	79.2 ± 18.0***	69.3 ± 21.4
Social	73.2 ± 28.5	85.0 ± 16.7***	76.4 ± 21.6
School	62.8 ± 24.2	81.3 ± 16.1***	68.3 ± 19.1*
Physical	73.2 ± 27.3	87.8 ± 13.1***	79.5 ± 17.1**
Total	69.4 ± 23.3	83.9 ± 12.5***	74.2 ± 15.4*
	Parental proxy-report		
	Epilepsy (n = 80)	**Healthy control (n ~8,690)**	**Chronic illness (n ~830)**
Emotional	64.7 ± 24.3	81.2 ± 16.4***	71.1 ± 19.8**
Social	68.9 ± 27.1	83.1 ± 19.7***	75.1 ± 21.8*
School	64.7 ± 23.5	78.3 ± 19.6***	65.6 ± 20.8
Physical	69.3 ± 29.2	84.1 ± 19.7***	77.0 ± 20.2**
Total	67.3 ± 22.8	82.3 ± 15.6***	73.1 ± 16.5**

Comparison of healthy controls and chronic illness controls with epilepsy.
* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$. Values are mean ± SD.

sample of children with epilepsy had significantly lower school functioning ($p < 0.05$), physical health ($p < 0.01$), and total ($p < 0.05$) scores. Owing to NPCCs (*i.e.* mental retardation/global developmental delay), only four of the 20 children with refractory seizures were able to complete the PedsQL.v4.0 measure, precluding separate analysis of this group.

Among children with well-controlled epilepsy, those with NPCCs had significantly lower scores across all domains ($p < 0.05$, $p < 0.001$) *(table 3)*. *Table 4* shows the correlation of demographic variables and seizure characteristics with the HRQOL scores. Duration of epilepsy was negatively correlated with PedsQL.v4.0 total score ($r = -0.35$, $p < 0.01$). The socioeconomic status of the family (Hollingshead) and parental age correlated positively with the child's psychosocial and total summary scores. Age at seizure onset, seizure frequency, and duration of diagnosis did not correlate significantly with the child's self-reported QOL scores.

Parent proxy-report

Parental PedsQL.v4.0 scores for children with epilepsy differed significantly from comparative normative data

Table 3. Comparison of PedsQL scores of children with well-controlled epilepsy with and without comorbidity and refractory epilepsy.

	Parent proxy-report scores		
	Group 1 (n = 46)	**Group 2 (n = 34)**	**Group 3 (n = 20)**
Emotional	69.2 ± 21.8	58.6 ± 26.4*	57.9 ± 26.0
Social	77.8 ± 25.1	56.4 ± 25.0***	39.5 ± 25.2***†
School	70.7 ± 25.6	56.6 ± 17.8**	43.3 ± 25.8***†
Physical	79.9 ± 24.0	54.5 ± 29.6***	51.1 ± 33.4***
Total aggregate	75.5 ± 21.1	56.1 ± 20.3***	48.0 ± 14.7***
	Child self-report scores		
	Group 1 (n = 42)	**Group 2 (n = 21)**	
Emotional	70.1 ± 23.8	54.5 ± 26.7*	
Social	80.2 ± 25.4	59.2 ± 29.9**	
School	70.0 ± 21.4	49.0 ± 23.6***	
Physical	79.9 ± 24.8	60.3 ± 27.8**	
Total aggregate	75.9 ± 20.8	57.0 ± 23.0***	

Comparison of group 1: well-controlled epilepsy without comorbidity; group 2: well-controlled epilepsy with comorbidity; group 3: refractory epilepsy; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; comparison of groups 2 and 3: † $p < 0.05$. Values are ± SD (range).

from healthy children ($p < 0.001$) across all individual domain scales and for total composite scores *(table 2)*. In comparison with the PedsQL scores for children with chronic medical conditions, parents of children with well-controlled epilepsy rated their child's emotional, social, physical, and total QOL scores as significantly lower ($p < 0.05$, $p < 0.01$). No significant differences were found between the two groups on the school functioning score.

The parents of children with refractory epilepsy rated the overall QOL of their children as significantly below ($p < 0.01$) the level reported for children with well-controlled epilepsy, except for emotional functioning *(table 3)*. These two groups did not differ in gender ($p = 0.33$), age ($p = 0.34$), or seizure frequency ($p = 0.30$) but differed in age at seizure onset and duration of epilepsy ($p < 0.001$).

Parental QOL scores also differed significantly ($p < 0.05$, $p < 0.001$) between children with well-controlled epilepsy with and without NPCCs *(table 3)*; however, no significant differences were found in total scores between children with well-controlled epilepsy with NPCCs and children with refractory epilepsy.

Table 4 lists correlations for demographics, seizure characteristics, and HRQOL measures. Total parental scores showed a positive correlation with the age of the father ($R = 0.43$, $p < 0.01$). Neither the duration of the average seizure nor seizure frequency correlated with parental total score.

Internal consistency

The Cronbach α for our sample was calculated for reliability of the measure and was 0.81 for the parents and 0.90 for the children for the various subscales of the HRQOL, exceeding the generally accepted criterion of 0.70 for adequate reliability in group comparisons.

Construct validity

Pretest hypotheses were analyzed to check construct validity of the instrument in paediatric epilepsy. As would be expected from previous evidence, we found a significant correlation between the HRQOL as measured by PedsQL.v4.0 and the duration of diagnosis of epilepsy (Hoare and Russell, 1995; Sabaz *et al.*, 2000; Hoare *et al.*, 2000) *(table 4)*; the severity of epilepsy (Hoare and Russell, 1995; Sabaz *et al.*, 2000; Camfield *et al.*, 2001; Austin *et al.*, 1996) (*table 3*); the number of medications (Sabaz *et al.*, 2000; Sabaz *et al.*, 2001) (data not shown); and the existence of NPCCs (Hoare and Russell, 1995; Camfield *et al.*, 2001) *(table 3)*.

Discussion

Our study supports the findings of other investigators that epilepsy has an adverse impact on children's quality of life. HRQOL scores were lower in our population compared with children with other chronic health conditions, corroborating earlier studies showing QOL to be more impaired in individuals with epilepsy compared with other medical conditions such as asthma (Modi *et al.*, 2009; Austin *et al.*, 1996). Areas of greatest concern for parents and children as reflected by lowest domain scores were school and emotional functioning. This finding is similar to previous studies of PedsQL that have reported emotional factors (Felder-Puig *et al.*, 2004) or school and emotional factors (Talarska, 2003) to be of most concern

Table 4. Correlation between HRQOL measures and seizure characteristics.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Parent PsSS	-													
2. Parent PhSS	0.59**	-												
3. Parent total	0.92**	0.85**	-											
4. Child PsSS	0.69**	0.6**	0.71**	-										
5. Child PhSS	0.57**	0.71**	0.68**	0.79**	-									
6. Child total	0.68**	0.68**	0.73**	0.97**	0.91**	-								
7. Aggregate total	0.87**	0.83**	0.95**	0.91**	0.86**	0.94**	-							
8. Child's age	- 0.07	0.04	- 0.02	0.09	0.01	0.06	- 0.05	-						
9. Mother's age	0.14	0.20	0.18	0.31*	0.36*	0.34*	0.23	0.36**	-					
10. Father's age	0.41**	0.39**	0.43**	0.42*	0.32	0.41*	0.47**	0.42**	0.84**	-				
11. Age at seizure onset	0.26*	0.3**	0.31**	0.22	0.15	0.20	0.3**	0.51**	0.45**	0.45**	-			
12. Duration of epilepsy diagnosis	- 0.33**	- 0.24*	- 0.33**	- 0.16	- 0.16	- 0.17	- 0.35**	0.45**	- 0.19	- 0.21	- 0.54**	-		
13. Length of average seizure	0.01	- 0.01	0.01	- 0.25*	- 0.3*	- 0.28*	- 0.03	- 0.15	0.01	- 0.08	- 0.01	- 0.13	-	
14. Length of longest seizure	- 0.15	- 0.10	- 0.14	- 0.16	- 0.18	- 0.17	- 0.16	0.18	0.01	- 0.25	- 0.17	0.37**	0.07	-
15. SES	0.18	0.14	0.18	0.3*	0.19	0.26*	0.21*	- 0.03	0.41**	0.56**	0.22*	- 0.21*	- 0.17	- 0.05

* Correlation is significant at the 0.05 level (2-tailed); ** correlation is significant at the 0.01 level (2-tailed). PsSS: psychosocial summary score; PhSS: physical summary score; SES: socioeconomic status.

in epilepsy. Other workers also recently demonstrated that global delay occurs across all domains of the parent proxy PedsQL scores in children who have had a single seizure or who have newly diagnosed, untreated epilepsy (Modi *et al.*, 2009).

Our study using the PedsQL.v4.0 shows a positive and very significant correlation between children with epilepsy and their parents for both the overall HRQOL scores and the physical, emotional, social, and school performance subscores. This suggests that the QOL as perceived by the parent closely approximates the self-perceived QOL by the child. These findings are comparable to those of a study using a German version of PedsQL.v4.0, to examine the impact of cancer and epilepsy, which also described good parent-child correlation, especially for epilepsy (Felder-Puig *et al.*, 2004). This agreement between parent and child perceptions of HRQOL is important in paediatric epilepsy, a condition in which young age or NPCCs can impair completion of HRQOL instruments.

Although we found a good correlation between the severity of epilepsy and HRQOL measures for parents, our study also underscores the importance of underlying NPCCs. In children with well-controlled epilepsy, parent and child perceptions of QOL were significantly better for children with epilepsy alone compared with those with comorbid conditions. The presence of such NPCCs appears to significantly reduce the perceived QOL compared with epilepsy in isolation. This finding is consistent with a similar comparison of parental HRQOL scores by Modi *et al.* (2009) among patients with a single seizure or newly diagnosed, untreated epilepsy.

An interesting finding in our study was the positive correlation between parental age and the child's psychosocial scores and overall QOL. Possible reasons for this finding include better economic situation or better coping mechanisms in older parents. The combined socioeconomic status of the parents, as measured by the Hollingshead scale, correlated with the emotional and school, but not the physical and social, subscores of the HRQOL. Neither the individual scores of the mother or father for education or employment, nor the combined index, correlated with any of the measures of HRQOL. This would seem to suggest that parental education or employment status does not impact the HRQOL. However, contrary to our findings, Devinsky *et al.* (1995) have shown positive HRQOL correlations with the educational and employment status of the parents, and Sabaz *et al.* (2003) have shown correlation with the estimated family income but not the educational status of the parents. Our study also corroborates work by previous investigators showing that age at seizure onset, duration of diagnosis, number of AEDs, and number of NPCCs all affect QOL in children with epilepsy (Hoare and Russell, 1995; Hoare *et al.*, 2000; Sabaz *et al.*, 2000; Camfield *et al.*, 2001; Sabaz *et al.*, 2001; Modi *et al.*, 2009).

The PedsQL.v4.0 is concise and convenient with only 23 items (18 for toddlers) yet is broad enough in assessing four domains of physical and social functioning. The instrument can be completed within five minutes (Modi *et al.*, 2009), which compares favourably with comprehensive instruments such as the QOLIE (Quality of Life in Epilepsy; 28 minutes) (Devinsky *et al.*, 1995) and the Impact of Childhood Illness Scale (15 minutes) (Hoare and Russell, 1995) and is well within the range of an average waiting room time in a busy outpatient clinic. Reviewing the results of the PedsQL.v4.0 would provide added depth to the clinical encounter without draining the clinician's time. Finally, because it provides information about patient concerns, a quality-of-life assessment as a brief, office-based psychological test may be reimbursable (Cramer *et al.*, 1996).

It is perhaps questionable whether generic HRQOL instruments are comparable to the in-depth and tailored assessment of the various components of HRQOL which epilepsy-specific instruments provide. A study comparing a generic measure of HRQOL (the Impact of Childhood Illness scale [ICI]) to epilepsy-specific measures (the Impact of Child Neurologic Handicap Scale [ICNH] and the Hague Restrictions in Epilepsy Scale [HARCES]) found that all three were adequate measures to assess HRQOL in intractable childhood epilepsy (Sherman *et al.*, 2002). Generic HRQOL measures such as the PedsQL.v4.0 remain valuable as they are portable across different diseases such as cancer, diabetes, arthritis, and epilepsy, many of which may be comorbid in the same individual. Another advantage of generic scales over epilepsy-specific scales is that they have been well validated (Carpay and Arts, 1996), as has the PedsQL.v4.0 (Varni *et al.*, 2001). A generic measure would also be better understood and deployed by a non-specialist physician or nurse.

Internal consistency and construct validity were demonstrated for PedsQL.v4.0 by measuring the HRQOL of children with epilepsy. The corroboration of the pretest hypotheses based on existing literature proved the construct validity of the instrument. However, we did not have test–retest data to validate this measure. The strong psychometric properties of the various HRQOL subscales, as measured by PedsQL.v4.0, make this a good instrument for future trials and clinical work.

The limitations of our study were as follows. As only three children had new-onset seizures (which were subsequently excluded), a comparison of HRQOL indices between new-onset and chronic epilepsy could not be done. However, this comparison has been done elsewhere using PedsQL (Modi *et al.*, 2009). A study coordinator supervised the completion of a proportion of the questionnaires and the rest were self-administered, limiting standardization of the testing situation. Data were not available regarding the proportion of patients who accepted the invitation to participate in the study *versus* those who declined.

A significant proportion of the subjects had NPCCs, which can affect HRQOL. However, NPCCs are expected to accompany epilepsy in real life, especially refractory epilepsy. Comparing the results to a previous report of normal children has an inherent weakness in variability of test administration settings. However, our comparison was based on seminal work proving the validity of PedsQL, which is potentially the best external benchmark available for this purpose.

Our research shows that the PedsQL.v4.0 assesses the various aspects of HRQOL in agreement with previously published literature. We have demonstrated good correlation between child self-report and parent proxy-report, thus establishing the PedsQL.v4.0 as a useful tool in situations in which child self-reporting is unreliable or unrealistic. A head-to-head comparison is needed for the validity of simpler instruments with more comprehensive measures which have been established as reliable in larger populations with epilepsy.

In summary, we demonstrate significant impairment in HRQOL among children with epilepsy compared with the normal population and children with other chronic health conditions. Neuropsychiatric comorbidities have a significant impact on HRQOL in this population. We demonstrate good concordance between parental and child perceptions of HRQOL using the PedsQL.v4.0 model. The ease of use and reliability of this instrument may make it valuable for routine use in the clinic. □

Disclosure
None of the authors has any conflict of interest or financial support to disclose.

References

Annegers JF. Epidemiology and genetics of epilepsy. *Neurol Clin* 1994; 12: 15-29.

Arunkumar G, Wyllie E, Kotagal P, Ong HT, Gilliam F. Parent- and patient-validated content for pediatric epilepsy quality-of-life assessment. *Epilepsia* 2000; 41: 1474-84.

Au A, Li P, Chan J, *et al.* Predicting the quality of life in Hong Kong Chinese adults with epilepsy. *Epilepsy Behav* 2002; 3: 350-7.

Austin JK, Huster GA, Dunn DW, Risinger MW. Adolescents with active or inactive epilepsy or asthma: a comparison of quality of life. *Epilepsia* 1996; 37: 1228-38.

Batzel LW, Dodrill CB, Dubinsky BL, *et al.* An objective method for the assessment of psychosocial problems in adolescents with epilepsy. *Epilepsia* 1991; 32: 202-11.

Camfield C, Breau L, Camfield P. Impact of pediatric epilepsy on the family: a new scale for clinical and research use. *Epilepsia* 2001; 42: 104-12.

Carpay HA, Arts WFM. Outcome assessment in epilepsy: available rating scales for adults and methodological issues pertaining to the development of scales for childhood epilepsy. *Epilepsy Res* 1996; 24: 127-36.

Carpay HA, Arts WFM, Vermeulen J, *et al*. Parent-completed scales for measuring seizure severity and severity of side-effects of antiepileptic drugs in childhood epilepsy: development and psychometric analysis. *Epilepsy Res* 1996; 24: 173-81.

Cramer JA, Perrine K, Devinsky O, Meador K. A brief questionnaire to screen for quality of life in epilepsy: the QOLIE-10. *Epilepsia* 1996; 37: 577-82.

Cramer JA, Westbrook LE, Devinsky O, Perrine K, Glassman MB, Camfield C. Development of the quality of life in epilepsy inventory for adolescents: the QOLIE-AD-48. *Epilepsia* 1999; 40: 1114-21.

Devinsky O, Vickrey BG, Cramer J, *et al*. Development of the Quality of Life in Epilepsy Inventory: the QOLIE-AD-48. *Epilepsia* 1995; 36: 1089-104.

Felder-Puig R, Frey E, Proksch K, Varni JW, Gadner H, Topf R. Validation of the German version of the Pediatric Quality of Life Inventory (PedsQL) in childhood cancer patients off treatment and children with epilepsy. *Qual Life Res* 2004; 13: 223-34.

Gilliam F, Wyllie E, Kashden J, *et al*. Epilepsy surgery outcome: comprehensive assessment in children. *Neurology* 1997; 48: 1368-74.

Hoare P, Mann H, Dunn S. Parental perception of the quality of life among children with epilepsy or diabetes with a new assessment questionnaire. *Qual Life Res* 2000; 9: 637-44.

Hoare P, Russell M. The quality of life of children with chronic epilepsy and their families: preliminary findings with a new assessment measure. *Dev Med Child Neurol* 1995; 37: 689-96.

Jacoby A. Epilepsy and the quality of everyday life: findings from a study of people with well-controlled epilepsy. *Soc Sci Med* 1992; 34: 657-66.

Jacoby A, Baker GA, Steen N, Potts P, Chadwick DW. The clinical course of epilepsy and its psychosocial correlates: findings from a UK community study. *Epilepsia* 1996; 37: 148-61.

Modi AC, King AS, Monahan SR, Koumoutsos JE, Morita DA, Glauser TA. Even a single seizure negatively impacts pediatric health-related quality of life. *Epilepsia* 2009; 50: 2110-6.

Norrby U, Carlsson J, Beckung E, Nordholm L. Self-assessment of well-being in a group of children with epilepsy. *Seizure* 1999; 8: 228-34.

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.

Sabaz M, Cairns DR, Lawson JA, Bleasel AF, Bye AM. The health-related quality of life of children with refractory epilepsy: a comparison of those with and without intellectual disability. *Epilepsia* 2001; 42: 621-8.

Sabaz M, Cairns DR, Lawson JA, Nheu N, Bleasel AF, Bye AM. Validation of a new quality of life measure for children with epilepsy. *Epilepsia* 2000; 41: 765-74.

Sabaz M, Lawson JA, Cairns DR, *et al*. Validation of the quality of life in childhood epilepsy questionnaire in American epilepsy patients. *Epilepsy Behav* 2003; 4: 680-91.

Schachter SC. Improving quality of life beyond seizure control. *Epileptic Disord* 2005; 7 (Suppl. 1): S34-8.

Sherman EM, Slick DJ, Connolly MB, *et al*. Validity of three measures of health-related quality of life in children with intractable epilepsy. *Epilepsia* 2002; 43: 1230-8.

Talarska D. Evaluating the life quality of children with epilepsy based on PedsQL [abstract]. Abstracts of the 10th Annual Conference of the International Society for Quality of Life Research (ISOQOL). *Qual Life Res* 2003; 12: 815.

Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. *Ambul Pediatr* 2003; 3: 329-41.

Varni JW, Seid M, Kurtin PS. PedsQL 4.0: Reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care* 2001; 39: 800-12.

Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the Pediatric Quality of Life Inventory. *Med Care* 1999; 37: 126-39.