A review of subjective impact measures for use with children and adolescents with epilepsy

Justin Cowan[1] & Gus A. Baker[2]
[1]*MRC Institute of Hearing Research, University Park, Nottingham University, Nottingham NG7 2RD, UK (E-mail: justin@ihr.mrc.ac.uk);* [2]*The University Department of Neurosciences, Clinical Sciences Centre for Research and Education, Lower Lane Fazakerely, Liverpool L9 7LJ, UK*

Abstract

Purpose: To evaluate measures of epilepsy-specific impact currently available for use with children and adolescents. The relative merits of the different measures are examined. *Method*: Four published epilepsy-specific impact measures, the Epilepsy and Learning Disabilities Quality of Life Scale (ELDQOL), the Health-related Quality of Life in Children with Epilepsy (HRQoLCE); the Impact of Childhood Neurologic Disability Scale (ICND), the Quality of Life in Epilepsy Inventory for Adolescents (QOLIE-AD-48), and the Quality of Life for Children with Epilepsy (QOLCE) were reviewed. *Results*: There exist several shortcomings with the available measures on various psychometric criteria with not one of the currently available measures reaching acceptable psychometric standards in terms of reliability and validity. Of note are the particular inadequacies in the validation of scale content; with there being no investigation of the existence of age or ability effects for the items in any of the questionnaires reviewed. *Conclusion*: There is a clear demand for a psychometrically robust measure of subjective impact of epilepsy for children and adolescents, which is applicable to a wide age and ability range. At present, the efforts of the Canadian Pediatric Epilepsy Network with the recent publication of a novel measure holds much promise for the future. It is advocated that further efforts are made to further establish the psychometric properties of these scales and for their integration within a comprehensive outcome model for use in the evaluation of clinical interventions.

Key words: Children, Epilepsy, Health-related quality of life, Outcome measurement

Abbreviations: AED – anti-epileptic drug; ELDQOL – Epilepsy and Learning Disabilities Quality of Life Scale; HRQoL – health-related quality of life; ICND – Impact of Childhood Neurologic Disability Scale; IPES – Impact of Paediatric Epilepsy Scale; QoL – quality of life; QOLCE – Quality of Life for Children with Epilepsy; QOLIE-AD-48 – Quality of Life in Epilepsy Inventory for Adolescents; SIE – subjective impact of epilepsy

Introduction

The importance of measuring health-related quality of life (HRQoL) is widely recognised and the last three decades has seen the emergence of quality of life measures across a number of different health conditions (e.g., arthritis, cancer, diabetes) [1]. The measurement of HRQoL in adults with epilepsy is now well-established and there exist a number of psychometrically robust measures [2]. The development of HRQoL measures for children and adolescents with epilepsy is lagging behind the developments in the adult field despite the increasing recognition of the need for such

measures, both as measures of impairment and as outcome measures for specific treatments [3].

There have been a number of recent initiatives to develop generic HRQoL scales for children and adolescents. For example, the Child Health Questionnaire [4] and the PedsQL [5] are designed to be generic instruments applicable to populations with different medical conditions. An advantage of these instruments is that they provide the opportunity to make comparisons between groups of children with different conditions [6]. However, the idiosyncratic nature of some conditions may result in generic measures neglecting some of the important issues related only to a particular condition and thus being poor at detecting change in clinical status. Because of this, disease-specific measures have been designed to be high fidelity instruments to assess the impact of those symptoms and treatment effects associated with a particular disease. The legitimacy of this approach has been confirmed with studies reporting that epilepsy-specific impact scales provide information that is over and above that provided by generic scales [7]. Despite there being similarities between both quality of life (QoL) and disease-specific impact concepts with both being multidimensional in nature and dependent on subjective judgements, QoL and HRQoL are generic concepts and are therefore theoretically distinct from judgements about the impact of a specific disease. Disease-specific impact measures should be viewed as a having distinct properties that are unique and highly sensitive to aspects of a specific disease. Distinguishing between these disparate constructs is essential for future gains in this field as different information will be gained from these measures. This has clear implications for the clinical and research utility of any scale, and is also relevant in any investigation of a measures criterion and construct validity.

Several instruments have been used within the paediatric epilepsy population to measure a variety of different constructs. Psychosocial functioning has been measured by instruments such as the Adolescent Psychosocial Seizure Inventory [8] and Norrby et al. [9] reported on a questionnaire to assess well-being (akin to psychosocial functioning). The above studies, and several subsequent studies employing these measures, should not be construed as assessments of QoL which is distinct from the assessment of simply physical, social or psychological functioning, variables which are predictors of QoL but not QoL itself.

Determining the impact of epilepsy and its treatment on the quality of life of a child or adolescent with epilepsy has proved to be difficult and elusive. There are a number of reasons for this including the fact that many of the measures have not been specifically designed for the purpose they are put to, as described above. Nor is there comprehensive evidence of their reliability, validity or sensitivity in the population under study even with those instruments specifically designed for this task. These obvious limitations restrict the ability of clinicians and researchers in the field to make precise statements about the effects of epilepsy and its treatment on quality of life.

The aim of this article is to systematically review de novo measures specifically developed to assess the subjective impact of epilepsy (SIE) and its treatment in children and adolescents, albeit often erroneous labelled as 'quality of life' measures. The restricted focus of this review to solely SIE instrument was deemed necessary by the plethora of self-report measures available and the different purposes to which these measures may be employed. We report the methodological problems in these studies including the assessment of reliability, validity and responsiveness of the measures used in populations of people with epilepsy.

Methods

The inclusion criteria for this review are subjective impact measures for use with children and adolescents with epilepsy. Measures will not be reviewed that assess QoL or HRQoL. A literature review was conducted that included searches of databases (PsycINFO and PubMed), manual searches of relevant journals and finally a review of the reference lists in identified articles. The criteria for assessing de novo measures were their construction attributes (the conceptual basis upon which any measure is developed) and their psychometric properties (scaling properties, reliability analysis, validity analysis and responsiveness). Descriptions of each of these criteria will not be detailed here due to space considerations but can be sought in various other publications [10, 11].

Results

There were four published measures that were identified from the literature search that purport to measures QoL in children and adolescents with epilepsy. The measures include the Epilepsy and Learning Disabilities Quality of Life Scale (EL-DQOL) [12], the HRQoL in Children with Epilepsy measure [13], the Impact of Childhood Neurologic Disability Scale (ICND) [14], the Quality of Life for Children with Epilepsy (QOLCE) [15, 16], and the Quality of Life in Epilepsy Inventory for Adolescents (QOLIE-AD-48) [17]. A further paediatric epilepsy QoL assessment inventory developed by Arunkumar et al. [18] was identified but was not reviewed as the measure is still under development (Wyllie, personal communication).

The Epilepsy and Learning Disabilities Quality of Life Scale

The ELDQOL has been developed by Baker et al. for use in community surveys and anti-epileptic drug (AED) trials assessing the quality of life of children with severe epilepsy and learning disabilities, diagnosed with Lennox–Gastaut Syndrome [12, 19–21]. Designed for completion by the parents or main caregiver of patients, the ELDQOL includes scales of seizure severity, AEDs side effects, mood behaviour disturbance, and items related to seizure severity, overall QoL, and overall health. Espie et al. [22] have previously reviewed this scale though no published information on the psychometric properties is available from the authors of the scale. The ELDQOL was described as having content validity, although the measure is not related to any conceptual model of QoL. Modest test–retest coefficients ($r = 0.67–0.87$) and internal reliability ($\alpha = 0.71–0.84$) were reported for the different subscales. Espie et al. concluded that the ELDQOL is relatively lengthy, perhaps more suited to overview than to outcome evaluation, as it is possible to derive component scores only from a few subsections. Further evidence of the psychometric properties of this measure is necessary before it could be considered a useful measure in clinical research. A study is currently being undertaken to provide further data on the psychometric properties of the scale.

The Health-related Quality of Life in Children with Epilepsy measure

Ronen et al. have reported on the development of two measures of HRQoL in Children with Epilepsy, a child self-report scale and a parent-proxy scale [13]. The items for the HRQoL measure were generated by an initial qualitative study using focus-groups which identified five major themes of HRQoL in childhood epilepsy [23, 24]. The response scale employs the format of alternative paired options of forced responses. Adequate scaling properties have been described with no significant ceiling or floor effects for any of the subscales and with scores being normally distributed. Item convergent validity in the form of corrected item-total correlations were reported for each of the children's subscales though not the parent-proxy data, nor was discriminant validity reported. Internal consistency of 0.7 or higher for all the subscale with the exception of the self-report subscale of *quest for normality* (0.63) and the parent-proxy subscale of *present worries* (0.64). Test–retest reliability over a two week period for the self-report measure was 0.59 or higher and for the parent-proxy measure was 0.60 or higher. It was not ascertained whether this group had clinically stable epilepsy during this period. The five subscales (interpersonal/social consequences, worries and concerns, intrapersonal/emotional issues, epilepsy my secret, and quest for normality) were developed and validated through the use of principle components analysis on a sizeable sample of 334 children. The analysis of the data from 424 parents revealed a 4-factor structure without the 'quest for normality' factor identified by the children and with the worries and concerns factors encompassing current and future items (whereas the children only identified current concerns).

An investigation of the associations of HRQoL scores to a range of clinical criteria including health care use (doctor and hospital visits), seizure severity, special educational needs, AED toxicity, number of AEDs taken, number of close friends, extracurricular activities, and the findings that both child and parent reports were significantly correlated with the majority of these variables supported the criterion validity of the measure.

In summary, Ronen et al. [13] have produced two related 25-item HRQoL instruments for

children with epilepsy aged 8–15, one a self-report measure and the other a parent-proxy measure. While providing a self-report measure for children with epilepsy the provision of a similar parent-proxy measure acknowledges that at times with this paediatric population proxy reports are necessary. The psychometric development of this questionnaire has been comprehensive with only the further evaluation of item discrimination across scales being desirable. Understandably, due to the infancy of the measure several further analyses have yet to be reported. Discriminant and concurrent validity of the measure with various patient populations and alternative measures will hopefully be forthcoming. The HRQoL measure has also yet to be used in a longitudinal study and so the measures responsiveness has yet to be ascertained.

The Impact of Childhood Neurologic Disability Scale

The recent development of the ICND [14] has built on the previous work on the Impact of Pediatric Epilepsy Scale (IPES) [25, 26] to enlarge the initial focus of the IPES solely on epilepsy to include the further areas of behaviour, cognition, and physical/neurological disability. Each area has the same 11 questions rated on a 4-point scale by a parent of children with epilepsy aged 2–18 years. Furthermore, the ICND includes a single overall quality of life item rated on a 6-point scale.

No reference has been made to the generation of the items or the target domains and so it is presumed that, as with the IPES, these were generated from the clinical experience of the authors and a literature review. The reliability and validity of the ICND was evaluated on a sample of 68 children with epilepsy, and 29 children with epilepsy and additional conditions. Item convergent validity was reported to be satisfactory though item discriminant validity was not reported. Internal consistency was excellent ($\alpha = 0.97$) and test–retest reliability conducted after an interval of 1–3 weeks produced a satisfactory intraclass correlation of 0.89.

Several steps were taken to ascertain the measures validity. Regarding criterion validity, scores on the ICND were compared to several clinical criteria with two groups of high and low total

ICND scores being analysed for associations with demographic and medical characteristics of the sample. It was found that children with a higher ICND total score had more comorbid diagnoses and more severe epilepsy. ICND total scores were also highly significantly negatively related to the quality of life item.

A principle components analysis was conducted to further investigate the construct validity of the ICND, though the 4×11 matrix design of the ICND is not amenable to this statistical analysis. Investigation of concurrent validation was conducted with the administration of several additional questionnaires tapping such constructs as family functioning, parenting stress, self-concept, and loneliness. It was found that children with high ICND scores also reported higher scores on measures of parenting stress, and emotional problems.

In summary, the brevity of the ICND makes it a clinically attractive instrument in terms of its ease and speed of use. However, its brevity and structure contribute to weaknesses in several of the psychometric properties required of a robust instrument. It is possible that the ICND could be of use in clinical practice to facilitate the identification of potentially problematic issues for patients with epilepsy, though it is not recommended for use in intervention outcome studies.

The Quality of Life for Children with Epilepsy

The QOLCE has been developed in Australia by Sabaz et al. [15] with the aim of producing an epilepsy-specific HRQoL questionnaire to assess a variety of age-relevant domains. Items were generated through a questionnaire survey to a group of 32 patients and guardians, a literature review, and a review of other published similar measures. The scale was developed for completion by parents of children with refractory epilepsy, aged 4–18 years with average intellectual abilities. The authors report that they are currently working on child self-report version for children aged 10 years and over.

The QOLCE consists of two parts, the first contains items assessing seizure description (56 items) and medication side effects (31 items). The second section contains 77 items specifically assessing the SIE in children with refractory epilepsy. These items contribute towards five QoL

Table 1. QoL domains and subscales of the QOLCE Part 2

QoL domain	Subscale (number of items)			
Physical function	Physical restriction (10)	Energy/fatigue (2)		
Cognitive function	Attention/concentration (5)	Memory (6)	Language (8)	Other cognitive (4)
Emotional well-being	Depression (4)	Anxiety (6)	Control/helplessness (4)	Self-esteem (5)
Social function	Social interactions (3)	Social activities (3)	Stigma (1)	
Behavioural function	Behaviour (15)			
QoL (1)				
Overall QoL (1)				

domains with 13 multi-item and 3 single-item subscales (see Table 1). The items are linearly transformed to a 0–100-point scale when scored. Inspection of ceiling and floor effects found that the social activities and stigma subscales both showed a significant percentage of responses at the ceiling (17.5 and 35.2, respectively) indicating that these subscale may have limited utility. Item convergent and discriminant validity was established. Internal reliability was reported as satisfactory with Cronbach's α ranging from 0.72 to 0.93. An analysis of test–retest reliability was not conducted.

Criterion validity (erroneously described in the article as 'sensitivity') was assessed by two clinical criteria of seizure severity and number of AEDs taken (adjusting for the child's age, age of seizure onset, gender and IQ). Seizure severity over the previous 6 months was negatively correlated with all of the QOLCE subscales, except depression, self-esteem, attention, and behaviour. Furthermore, a significant inverse relationship was found between the number of AEDs taken and the QOLCE subscale of memory and language.

Subscale correlations were reported as evidence of the construct validity of the QOLCE as the low sample size (n = 63) precluded the use of factor analysis, a significant shortcoming in the development of the measure. Convergent validity assessed by the administration of two generic measures of child health and correlation coefficients were reported for theoretically similar and dissimilar constructs between the QOLCE and these scales.

In a subsequent investigation, Sabaz et al. [16] conducted a study within which parents of children with mild to moderate learning disability (n = 30) were compared in their performance on the QOLCE with parents of children with average intelligence (n = 64). For both groups, the QOLCE was found to discriminate on the clinical variables of age at epilepsy onset, number of AEDs taken and seizure frequency. It was also found that the presence of intellectual disability in children with epilepsy independently depresses scores on the QOLCE. These results need to be treated with caution as the QOLCE was developed for children with average intelligence, and there is no published data regarding the psychometric properties of the QOLCE's with children with learning disabilities.

In summary, though the QOLCE is an attempt to develop a sophisticated and comprehensive instrument there are several shortcomings to this measure. The construction of some of the subscales with a low number of items (one subscale only consists of one item) is problematic in establishing acceptable reliability of these subscales. Though the QOLCE is intended for use with a large age range, no examination of the possible existence of age effects is reported. This measure also suffers from the use of a restricted sample of children with epilepsy in the development of the scale, with the QOLCE not being suitable for children with learning disabilities. The small sample size and lack of test data further limit the quality of the QOLCE's psychometric properties.

The Quality of Life in Epilepsy Inventory for Adolescents

The QOLIE-AD-48 [17] is a self-report scale for adolescents 11–17 years of age. Though no theoretical model for the scale is described, the QOLIE-AD-48 does conform to the criteria outlined above for an SIE measure. As the scale is a self-report measure it is limited to adolescents with average intelligence. The scale consists of 48 items which were based on a literature review, a review of existing measures, focus groups with adolescents with epilepsy, and expert professional opinion. These items are rated on a 5-point scale and

divided into eight subscales: epilepsy impact, memory/concentration, attitudes toward epilepsy, physical functioning, stigma, social support, school behaviour, health perceptions, and a total summary score. Analysis of the scaling properties found that no floor or ceiling effects were detected and the range of scores for all subscales was 0–100 indicating a good range of responses.

Internal reliability of the QOLIE-AD-48, estimated by Cronbach's α coefficient, was 0.74 for the summary score and was within acceptable limits for the subscales (ranging from 0.73 to 0.94) within the exception of a low coefficient of 0.52 for the health perceptions subscale. Test–retest reliability was conducted over a period of 4 weeks and was found to be 0.83 for the summary score. Though the exclusion criteria for participants included those who had brain surgery in the previous year or a change in AEDs in the preceding 4 months, it was not established that the test–retest group had stable epilepsy over this period.

Regarding the validity of the QOLIE-AD-48, the correlations of each item to its own subscale, or to other subscales are not reported and so it cannot be judged on item convergent or discriminant validity. Criterion validity was established with the QOLIE-AD-48 being found to significantly discriminate between groups differing in seizure severity with scores significantly decreasing as seizure severity increased. A subsequent study [27] reported that older adolescents, those with more severe epilepsy and more symptoms of neurotoxicity, and those living in households with lower socio-economic status were more likely to report greater overall SIE. Convergent validity was assessed with two external scales of self-efficacy and self-esteem correlations of 0.65 and 0.54, respectively, being found. The authors reported that internal validity was demonstrated by a factor analysis that produced a single factor solution for the eight dimensions. However, there is a general factor in principle components and principle factor analysis which is an artefact of the algebraic procedures, thus obtaining a general factor in the factor analysis of items is not as informative as it may seem [28]. The second-order factor structure, with the information of how each item loaded on the different subscales, was not reported.

A double cross-validation procedure was conducted using factor analysis during which the sample was randomly divided into two halves and the factor structure obtained from the first sample was then verified with the second sample. This process was then repeated in reverse and then conducted on the entire sample. Items that matched in both half samples and then in the entire sample were retained, resulting in 8 scales and 48 items. The reduction in the sample size as the consequence of this statistical procedure (the initial sample of 191 participants is necessarily halved) and the large number of items (88) is contrary to the recommended sample size for use with factor analysis. It remains to be seen whether the factor structure found can be replicated in an independent sample of suitable size and also whether the factor structure differs according to gender.

In summary, the QOLIE-AD-48 has undergone a careful development process and meets many of the psychometric criteria necessary for a robust instrument. Though the scale has been employed in studies showing it's discriminatory power [27], further investigation of the construct validity of the scale on sizeable populations is still required. The most significant shortcoming of the QOLIE-AD-48 is that it is restricted to use by adolescents aged 11–17 without learning disabilities.

Discussion

This review of the paediatric SIE measures has shown that the available measures have shortcomings with respect to various psychometric properties. Though not one of the currently available measures reaches acceptable psychometric standards to establish satisfactory reliability or validity (see Table 2), this is largely due to the infancy of some of the measures with further studies needed. Of particular note is the promising HRQoL in Children with Epilepsy measure recently reported on by Ronen et al. [13].

This paper has distinguished between the concepts of QoL, HRQoL, and disease-specific subjective impact and focused on published measures of the third of these constructs in the belief that such measures offer the greatest potential utility for both clinicians and researchers attempting to assess levels of impairment or the outcome of specific treatments in individuals with epilepsy. The importance of distinguishing between these

Table 2. A summary of the performance of each scale on the evaluation criteria

	ELDQOL	HRQoLCE	ICND	QOLCE	QOLIE-AD-48
Age range	2–18 years	8–15 years	2–18 years	4–18 years	11–17 years
Respondent	Parent	Child and parent	Parent	Parent	Adolescent
Suitability for use for patients with learning disability	Yes	Yes	Yes	No	No
Derivation of item pool	Yes	Yes	Poor	Yes	Yes
Investigation of age, gender or ability effects	No	No	No	No	No
Multiple domains	Yes	Yes	No	Yes	Yes
Adequate scaling properties	Not reported	Yes	Not reported	Poor	Yes
Item convergent or discriminant validity	Not reported	Partially reported	Not applicable	Yes	Not reported
Internal reliability	Yes	Yes	Yes	Yes	Poor (health sub-scale)
Test–retest reliability	Yes	Moderate	Yes	Not conducted	Yes
Criterion validity (clinical criteria)	Not conducted	Yes	Yes	Yes	Yes
Construct validity (discriminant and concurrent validity)	Not conducted	Not conducted	Poor	Poor	Poor
Responsiveness	Yes	Not conducted	Not conducted	Not conducted	Not conducted

ELDQOL – Epilepsy and Learning Disabilities Quality of Life scale; HRQoLCE – Health-related Quality of Life in Children with Epilepsy measure; ICND – Impact of Childhood Neurologic Disability scale; QOLCE – Quality of Life for Children with Epilepsy; QOLIE-AD-48 – Quality of Life in Epilepsy Inventory for Adolescents.

disparate constructs is essential for future gains in this field. Only recently, in an extensive review of 'quality of life' measures for children with chronic illness, a generic HRQoL measure was categorised alongside a disease-specific measure, neglecting this fundamental theoretical distinction. The authors then proceeded to conclude that one of the problems associated with measurement of QoL in children was that there was much confusion about the definition and measurement of QoL [29].

As we are dealing with a paediatric population the relevance of developmental issues becomes highly significant as it is very likely that the relevance of certain issues will varying according to age. Though this issue is perhaps not as pertinent for a scale such as the QOLIE-48-AD with its narrow age range it still requires addressing. For instance, the impact of being prevented from driving will be far more salient for a 17-year-old than for an 11-year-old. Whether there are any differences dependent upon gender has not been established in any of the above measures. It is also the case that the issues that are impacting on youngsters with learning disabilities are potentially different to those of children of normal intelligence. It flies in the face of accepted practice to use a measure that has been validated for use with individuals of normal intelligence on a population with learning disabilities. The existence or absence of age, gender and ability effects needs to be addressed as it is possible that these shortcomings have implications for a measures capacity for detecting significant clinical change.

There is little information of the responsiveness to clinical change of any of the measures reviewed here. This is a notable absence as one of the central justifications for the existence of these measures is for use as clinical outcome measures. If such studies are produced in the near future, as is the case with similar adult measures [30, 31], it remains to be seen what the relative sensitivity is between these measures. As several of the measures reviewed have not comprehensively addressed each of the several psychometric properties required of a robust SIE measure, it must be anticipated that any responsiveness index reported in the future for these measures is likely to be an underestimate of the maximum potential for a SIE measure.

Despite these limitations, the research efforts in this field are in the early stages and offer much promise for the future. There are several strengths present in both the QOLIE-AD-48 and the QOLCE that need to be highlighted. First, both scales have incorporated a generic measure of HRQoL, an approach that is to be commended in the development of an outcome battery for a population with a chronic condition [32]. The use

of a generic and disease-specific HRQoL measure not only facilitates comparisons between groups of children with different chronic diseases but also permits the investigation of incremental validity, an issue that remains to be demonstrated within paediatric populations. Recently, researchers have conducted a cross-validation study of a generic HRQoL measure, a SIE measure, and a measure that focused on one aspect of the burden of living with epilepsy [33]. The study highlighted the different information gained from these measures and different potential uses that these measures could be put to. It is the authors' opinion that such a combined approach is likely offer the greatest utility.

Whereas adult measures are beginning to meet most of the criteria for an acceptable measure, possible paediatric candidates are only just emerging. In offering guidance for future research efforts several issues remain to be addressed, including delineating the desired age and ability range of a SIE measure and conceptualising SIE within a comprehensive outcome model.

The appropriate age and ability range of a paediatric measure of SIE can be determined by defining the use to which the measure will be put to and the characteristics of the population it will be used with. As one of the purposes of the instrument will be as an outcome measure in longitudinal studies investigating clinical change over substantial periods, it is desirable that the measure be applicable to a wide age range. This can be evidenced by the demand for such a measure in outcome studies of epilepsy surgery [34], studies which require the use of a time frame spanning several years [35]. It is likely that the development of a measure with a wide age range has been hindered as the most appropriate methodology is the self-report questionnaire. Despite the advocacy of self-report questionnaires for children [29, 32], this is problematic given the developmental considerations of measurement with some children with epilepsy (i.e., too young or cognitively impaired). It is therefore necessary that at times data be obtained from parents or carers though there remains a need for a parallel child or adolescent self-report versions an approach adopted by Ronen et al. [13].

The existence of learning disabilities in a significant proportion of children with epilepsy [35] and the fact that these youngsters tend to be the focus of a considerable amount of clinical atten-

tion, indicates that research efforts in developing a SIE measure need to be focused towards, or inclusive of, children with epilepsy of varying degrees of learning disability. Unfortunately, there currently exists no available measure that can be used with children with learning disabilities [33].

In conclusion, as there are several shortcomings in the currently available measures, there is a clear demand for a measure of SIE for children and adolescents with robust psychometric properties and applicable to a wide age and ability range. At present, the efforts of the Canadian Pediatric Epilepsy Network [13] hold much promise for the future. It has been proposed that a comprehensive outcome battery should incorporate a generic QoL measure, a HRQoL measure (to enable between illness comparisons) and an SIE (to maximise the sensitivity to clinical interventions). The inclusion of the clinical criteria of seizure type, frequency, and ratings of seizure severity and side effects of medication is also necessary. Given the high cost of provision for epilepsy to public, social, educational and health services it is perhaps surprising that more effort has not been directed towards the development of a measure that is vital in determining the relative efficacy of any intervention.

Acknowledgements

References

1. Baker GA, et al. The initial development of a health-related quality of life model as an outcome measure in epilepsy. Epilepsy Res 1993; 16(1): 65–81.
2. Baker GA, et al. Commission on Outcome Measurement in Epilepsy, 1994–1997: Final report. Epilepsia 1998; 39(2): 213–231.
3. Carpay HA, 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(3): 173–181.
4. Landgraf JM, Abetz L, Ware JE. The CHQ: A User's Manual. Boston, MA: The Health Institute, New England Medical Centre, 1999.
5. Varni JW, Seid M, Rode CA. The PedsQL: Measurement model for the pediatric quality of life inventory. Med Care 1999; 37(2): 126–139.

6. Miller V, Palermo TM, Grewe SD. Quality of life in pediatric epilepsy: Demographic and disease-related predictors and comparison with healthy controls. Epilepsy Behav 2003; 4(1): 36–42.

7. Wagner AK, et al. Advances in methods for assessing the impact of epilepsy and antiepileptic drug therapy on patients' health-related quality of life. Qual Life Res 1995; 4(2): 115–134.

8. Batzel LW, et al. An objective method for the assessment of psychosocial problems in adolescents with epilepsy. Epilepsia 1991; 32(2): 202–211.

9. Norrby U, et al. Self-assessment of well-being in a group of children with epilepsy. Seizure 1999; 8(4): 228–234.

10. Cramer JA. Principles of health-related quality of life: Assessment in clinical trials. Epilepsia 2002; 43(9): 1084–1095.

11. Nunnally JC, Bernstein IH. Psychometric Theory. New York: McGraw-Hill, 1994.

12. Jacoby A, et al. Lamotrigine as add-on therapy is associated with improvement in mood in patients with severe epilepsy. Epilepsia 1996; 37(Suppl. 5): 202.

13. Ronen GM, Streiner DL, Rosenbaum P. Health-related quality of life in children with epilepsy: Development and validation of self-report and parent proxy measures. Epilepsia 2003; 44(4): 598–612.

14. Camfield C, Breau L, Camfield P. Assessing the impact of pediatric epilepsy and concomitant behavioral, cognitive, and physical/neurologic disability: Impact of Childhood Neurologic Disability Scale. Dev Med Child Neurol 2003; 45(3): 152–159.

15. Sabaz M, et al. Validation of a new quality of life measure for children with epilepsy. Epilepsia 2000; 41(6): 765–774.

16. Sabaz M, et al. The health-related quality of life of children with refractory epilepsy: A comparison of those with and without intellectual disability. Epilepsia 2001; 42(5): 621–628.

17. Cramer JA, et al. Development of the quality of life in epilepsy inventory for adolescents: The QOLIE-AD-48. Epilepsia 1999; 40(8): 1114–1121.

18. Arunkumar G, et al. Parent- and patient-validated content for pediatric epilepsy quality-of-life assessment. Epilepsia 2000; 41(11): 1474–1484.

19. Baker GA, Jacoby A, Douglas C. Quality of life outcomes of lamotrigine used in the treatment of patients with severe epiletpic syndromes. Epilepsia 1996; 37(suppl. 4): 117.

20. Baker GA, Jacoby A. Quality of life assessment with add-on Lamictal (Lamotrigine) in children and adults with epilepsy and learning disability. Epilepsia 1997; 38(Suppl. 3): 108.

21. Jacoby A, Baker GA, Appleton R. Quality of life of children with epilepsy: Findings from a UK Community study. Epilepsia 1996; 37(Suppl. 4): 100.

22. Espie CA, et al. Development and validation of the Glasgow Epilepsy Outcome Scale (GEOS): A new instrument for measuring concerns about epilepsy in people with mental retardation. Epilepsia 2001; 42(8): 1043–1051.

23. Ronen GM, et al. Health-related quality of life in childhood epilepsy: The results of children's participation in identifying the components. Dev Med Child Neurol 1999; 41(8): 554–559.

24. Ronen GM, et al. Health-related quality of life in childhood disorders: A modified focus group technique to involve children. Qual Life Res 2001; 10(1): 71–79.

25. Camfield C, Breau L, Camfield P. Impact of pediatric epilepsy on the family: A new scale for clinical and research use. Epilepsia 2001; 42(1): 104–112.

26. Camfield C, Breau L, Camfield P. Impact of pediatric epilepsy scale: A pilot study. Canadian Psychol 1999; 40: 53.

27. Devinsky O, et al. Risk factors for poor health-related quality of life in adolescents with epilepsy. Epilepsia 1999; 40(12): 1715–1720.

28. Kline P. An Easy Guide to Factor Analysis. London: Routledge, 1994.

29. Eiser C, Morse R. A review of measures of quality of life for children with chronic illness. Arch Dis Child 2001; 84(3): 205–211.

30. Wiebe S, et al. Clinically important change in quality of life in epilepsy. J Neurol Neurosurg Psychiatry 2002; 73(2): 116–120.

31. Kim S, et al. Responsiveness of the quality of life in epilepsy inventory (QOLIE-89) in an antiepileptic drug trial. Qual Life Res 2003; 12(2): 147–155.

32. Levi R, Drotar D. Critical issues and needs of health-related quality of life assessment in children and adolescents with chronic health conditions. In: Drotar D (ed.), Measuring Health-related Quality of Life in Children and Adolescents, Erlbaum: NJ, 1998; 3–24.

33. Sherman EM, et al. Validity of three measures of health-related quality of life in children with intractable epilepsy. Epilepsia 2002; 43(10): 1230–1238.

34. Rossi GF. Evaluation of surgical treatment outcome in epilepsy. Crit Rev Neurosurgery 1998; 8(5): 282–289.

35. Sillanpaa M. Social functioning and seizure status of young adults with onset of epilepsy in childhood. An epidemiological 20-year follow-up study. Acta Neurol Scand Suppl 1983; 96: 1–81.

Address for correspondence: Justin Cowan, MRC Institute of Hearing Research, University Park, Nottingham University, Nottingham NG7 2RD, UK
Phone: +44-0-115-951-8508 ext. 250; Fax: +44-0-115-951-8503
E-mail: justin@ihr.mrc.ac.uk