

Self-assessment of well-being in a group of children with epilepsy

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Epilepsy is common in childhood, the prevalence being about five per 1000 children. The purpose of this study was to assess well-being in children with controlled epilepsy (but did not include those with obvious neurodeficits such as mental retardation or cerebral palsy) and compare them with age-matched healthy children. The patient group comprised of 31 children, 12 boys and 19 girls, whereas the control population group consisted of 342 children, 176 boys and 166 girls who were all in good health. All children involved in the study were aged between 9–13 years. A questionnaire was distributed to the children to complete. It consisted of 39 bipolar adjectives and a visual analogue scale was employed. The results show that the group of children with controlled epilepsy did not differ significantly from the age-matched control group. There was no significant difference between the sexes except for the dimension of vitality, where the boys scored better than the girls. Thus the well-being of children with controlled epilepsy seems to be similar to that of children from a control population. The psychometric properties of the instrument were also assessed. An assessment of well-being in children with intractable epilepsy, using a similar approach, is in progress.

Key words: childhood epilepsy; questionnaire; self-assessment; well-being.

INTRODUCTION

Epilepsy is one of the most common chronic neurological conditions in childhood, with a prevalence of about five per 1000 children^{1–4}. In 70–80 percent of children with uncomplicated epilepsy, seizures are controlled by antiepileptic drugs (AEDs). The population of children with epilepsy is very heterogeneous, with additional neurodeficits such as mental retardation (MR) and cerebral palsy (CP) in approximately one-third^{2,5}. In children with such additional disabilities, the seizures are often not controlled by AEDs^{1–6}.

For children with epilepsy, childhood is often a troublesome time, with hospitalizations and consultations with doctors, complicated and stressful treatments and limitations to everyday life⁷. These children are far more exposed to stress of different kinds, such as physical, mental and social. Severe epilepsy constitutes a heavy burden for the child, the family, the health care system and society in terms of personal suffering, staff requirements and economic resources^{8,9}. Although epilepsy is the main problem, motor and sensory dysfunctions often occur at the same time and are frequently neglected and rarely investigated in detail. Such dysfunctions may be due to

the underlying cause of the epilepsy, the epilepsy itself, the medication or a combination of these factors^{10,11}. Previous research has mainly used seizure control as the sole goal for successful treatment, but to provide adequate treatment and care, it is important not only to focus on seizures, but also to assess cognitive, motor and sensory functions as well as psychosocial aspects. The anxiety that epilepsy can engender for the child and family over the ordinary but, nevertheless, important aspects of the child's life such as scholastic progress or family trips and holidays, has been largely ignored as a research topic. Consequently, improving the quality of life (QoL) of children with epilepsy remains an important issue¹². There is also little understanding about how the child's and the family's views on the influence of epilepsy on their lifestyle differ from those of professionals and researchers¹³.

To better understand and meet the children's needs, instruments addressing children themselves are required. Wiklund *et al.*¹⁴ developed such an instrument, a visual analogue scale, with which to measure well-being in children in Sweden. Visual analogue scales are well documented, sensitive to small changes and, therefore, often used in clinical trials¹⁵.

The aims of this study were:

- to assess well-being in children with epilepsy in three different grades (age 9–13 years) and to compare these groups with age-matched healthy population groups;
- to compare the well-being between the sexes in the patient group; and
- to further assess the psychometric properties of the instrument by examining its internal consistency and construct validity.

MATERIALS AND METHODS

Patient group

A sample of 31 children with epilepsy were recruited from an earlier study¹¹. They consisted of 12 boys and 19 girls aged between 9–13 years (Table 1). They were registered as outpatients at the Children's Hospital, Sahlgrenska University Hospital, Östra, Göteborg, Sweden. The children were not mentally retarded and had no cerebral palsy or other obvious neurodeficits such as visual loss, hearing impairments, behavioural, attentional or psychiatric problems¹⁶. Primarily generalized epilepsy was present in 41 percent and localization related epilepsy in 58 percent of the children. The mean age at onset of epilepsy was 5.3 years. The types of epilepsy were classified according to the Commission of the ILAE^{17,18} and are shown in Table 2. Two children had daily seizures, two had some seizures monthly and two children had three to four seizures per year. Seven children had been seizure free without medication for 4 months or more, and 18 children were seizure free without medication. None of the children had difficulties in understanding the Swedish language. The study has been approved by the Ethics Committee of Göteborg University, and all of the children and parents participating were provided with written and oral information about the study.

Table 1: Age and sex distributions of the patient group and the control population group.

Age (years)	Girls (n)	Boys (n)	Total (n)
Patient group			
9	6	4	10
11	10	6	16
13	3	2	5
Total	19	12	31
Control population group			
9	58	59	117
11	54	62	116
13	54	55	109
Total	166	176	342

Table 2: Combined distribution of epilepsies and seizure types in 31 children with epilepsy 9–13 years of age^{16,17}.

Localization-related (n = 18)	
<i>Idiopathic</i>	
Benign childhood epilepsy	6
<i>Symptomatic/Cryptogenic</i>	
Simple partial seizures	0
Complex partial seizures	10
Secondary generalized seizures	2
Primarily generalized (n = 13)	
<i>Idiopathic with</i>	
Absences	6
Tonic-clonic seizures	7

Control population group

The control population group consisted of 342 healthy boys and girls, aged 9, 11, and 13 years from Göteborg (Table 1)¹⁴.

The well-being questionnaire

The questionnaire is an easily administered, short and simple adjective test and contains 39 bipolar adjectives. For each adjective pair, the children marked a visual analogue scale (VAS), which consists of a straight line 100 mm in length. The endpoints were defined by words denoting the extreme opposites of the attribute to be measured, for example; safe–unsafe, happy–sad, afraid–unafraid. The questionnaire was tested on the control group of 342 healthy children 9, 11 and 13 years old. Factor analysis confirmed that the items selected to form the measure were valid and could be combined into six separate dimensions covering *alertness*, *self-esteem*, *mood*, *elation*, *stability* and *vitality*. High internal consistency reliability was found for all dimensions¹⁴. In an earlier study, the children seemed to have no difficulties in completing the questionnaire. Children from the age of 9 years understood the instructions well and there were very few questions about the meaning of the words¹⁴.

Procedure

Thirty-six families were contacted by letter and asked if they would participate in the study. After 3 weeks, the first author (UN) contacted the families to obtain their answers and arrange appointments. Two of the families had moved to another city. One family was not possible to reach by telephone and one family did not want to participate in the study. One family did not come to the appointment. The patient group finally consisted of

31 children. The questionnaire was given to the children to answer in their homes and UN was present to answer questions about the instrument. For all but one child the procedure took place in the afternoon, after school was finished. The parents were not always present but when they were they did not interfere with the procedure. The questionnaire was answered in, at most, 30 minutes. No other measurements were performed.

Statistical analysis

A 95 percent confidence interval for the mean difference was used for the comparison of means between groups. The Pearson product-moment correlation was used for calculation of the intercorrelations between factors. The Cronbach's coefficient alpha was used to determine the internal consistency¹⁹. For all tests *P* was set at the 0.05 level of significance.

RESULTS

Comparison of well-being between the patient group and the control population group

All questions were responded to by all of children involved. Means and standard deviations of the various dimensions of well-being are shown for the patient group as well as the control population group, for each age group respectively (Tables 3–5). For the mean difference, a 95% confidence interval was used when comparing grade 3 (age ~ 9), grade 5 (age ~ 11) and grade 7 (age ~ 13) of the patient group with the same grades of the control group on each of the six dimensions of well-being, but, since the confidence intervals included 0, no significant differences were found (Tables 3–5).

Comparison between sexes in the patient group

An analysis of the impact of gender in the patient group showed that there were no statistically significant differences except for the dimension of vitality (95% confidence interval was -22.6 to -0.2), where the boys scored better than the girls (Table 6). A comparison was also made between the patient group and the control population group within each gender group as to vitality. However, the mean vitality of boys with epilepsy ($M = 68.8$) did not differ significantly from that of the healthy boys ($M = 62.8$). Nor did the epileptic girls differ from the healthy girls ($M = 57.4$ and $M = 56.8$, respectively).

Psychometric properties of the instrument

Internal consistency coefficients ranged between 0.36 and 0.85 for the six dimensions. There was a good agreement between the two groups of epileptic and healthy children except for the dimension of elation, which only had an alpha coefficient of 0.36 in the patient group. In order to gain some knowledge about the construct validity of the well-being scale, the various dimensions were intercorrelated. The results are presented in Table 7.

DISCUSSION

The children of this study had controlled epilepsy and are not representative of the total population of children with epilepsy. The mean age of onset of epilepsy was 5.3 years. Seven of the 31 children had the benign form of childhood epilepsy.

The lack of adequate assessment instruments has limited our knowledge of well-being in children with epilepsy. Most instruments available are not designed to address the children themselves. Instead, the parents have estimated their child's well-being^{20,21}. It has been reported that children's self-rated quality of life does not correspond with parents' ratings on some dimensions, indicating the need to obtain children's self-reports as well^{15,22–24}. When parents of kidney-transplanted children were asked about the problems of changed appearance and poor growth in their children, only two out of 29 sets of parents spoke about these questions. The results might have been different had the children themselves been asked the same questions²⁵.

Perceived well-being is a highly subjective variable, on which it is feasible to obtain information by asking the person concerned directly. To use a self-administered questionnaire is one way to obtain the relevant information in a systematic manner and to make quantification simple¹⁵.

There are two critical aspects of a questionnaire for children: the level of reading comprehension and the time needed for completion of the questionnaire. The questionnaire should be short enough to make it possible to complete within the child's attention span. Instructions should be clear and straightforward and the questions simple and easy for children to answer. These criteria were met in the present study. The visual analogue scales which were used are understood by children, sensitive to small changes and are, therefore, often used in clinical trials¹⁵.

Most children filled in the questionnaire without any problems. Three children answered the questions somewhat later in the afternoon than the others and seemed tired and were not fully concentrated on the

Table 3: Comparison between grade 3 (age ~ 9) in the patient group and in the control population group on the dimensions of well-being.

Dimensions of well-being	Patient group grade 3 (age ~ 9) (n = 10)		Control population group grade 3 (age ~ 9) (n = 117)		95% confidence interval for the mean difference
	Mean	SD	Mean	SD	
Alertness	68.9	12.9	69.7	13.1	-7.7 to 9.3
Self-esteem	63.8	12.7	64.2	15.1	-9.3 to 10.1
Mood	76.3	7.7	73.7	17.4	-13.6 to 8.4
Elation	47.5	11.0	55.0	12.7	-0.7 to 15.7
Stability	72.5	12.1	68.7	17.5	-15.0 to 7.4
Vitality	69.7	21.3	64.6	17.5	-16.7 to 6.7
Total score	66.4	8.7	66.3	10.4	-6.8 to 6.6

Note: the higher the score, the greater the feeling of well-being.

Table 4: Comparison between grade 5 (age ~ 11) in the patient group and in the control population group on the dimensions of well-being.

Dimensions of well-being	Patient group grade 5 (age ~ 11) (n = 16)		Control population group grade 5 (age ~ 11) (n = 116)		95% confidence interval for the mean difference
	Mean	SD	Mean	SD	
Alertness	66.73	14.81	66.0	12.9	-6.4 to 7.9
Self-esteem	66.19	12.78	62.0	12.8	-2.8 to 11.1
Mood	72.46	17.88	71.7	14.9	-7.5 to 9.1
Elation	52.57	13.63	53.3	12.8	-7.7 to 6.3
Stability	74.48	15.91	67.6	16.9	-2.3 to 16.0
Vitality	58.93	12.54	60.9	17.6	-11.3 to 7.3
Total score	65.23	11.28	63.5	9.5	-3.6 to 7.0

Note: the higher the score, the greater the feeling of well-being.

Table 5: Means and standard deviations in grade 7 (age ~ 13) of the patient group and of the control population group on the dimensions of well-being.

Dimensions of well-being	Patient group grade 7 (age ~ 13) (n = 5)		Control population group grade 7 (age ~ 13) (n = 109)		95% confidence interval for the mean difference
	Mean	SD	Mean	SD	
Alertness	58.9	9.7	63.5	14.2	-17.3 to 8.1
Self-esteem	60.7	9.4	62.4	14.9	-15.0 to 11.7
Mood	72.4	7.8	68.1	16.0	-9.6 to 18.9
Elation	51.6	9.0	53.9	11.7	-10.1 to 7.5
Stability	68.6	15.4	69.1	16.4	-14.2 to 12.2
Vitality	55.7	8.5	53.8	20.7	-15.2 to 19.0
Total score	61.3	6.4	61.7	10.4	-9.0 to 8.2

Note: the higher the score, the greater the feeling of well-being.

task. This could possibly be due to the late hour in the afternoon and/or the medication. UN was present, so the children could ask if anything appeared difficult to understand. Two of the youngest children had questions about the meaning of the words self-confidence, unenterprising and self-controlled, probably due to their young age. Most of the older children and many of the younger ones had no questions at all. A minimum age of 9 or 10 years has been recommended for self-assessment of subjective concepts such as behaviour and self-esteem²⁶.

The internal consistency explores the degree of relationship among individual items that combine into a dimension¹⁴. There was a good correspondence between the groups in all dimensions except for the dimension of *elation*, which had an alpha coefficient of only 0.36 in the patient group. Thus, this dimension was not consistent in the patient group. Construct validity is particularly important when concepts are measured that

cannot be examined directly but can only be inferred from behaviour (hypothetical constructs)²⁷. One way of assessing construct validity is to correlate a scale with other known scales. In order to gain understanding about the construct validity of the well-being scale which was used in the present study, the various dimensions were intercorrelated in the patient group. When comparing the result with the control population group, it was found that the patient group had higher correlations on seven of the reported relationships, but the pattern was essentially similar. Thus, the results indicate that the questionnaire is appropriate and applicable in children with controlled epilepsy.

Most of the results of the patient group corresponded to those of the control population and no significant differences were found. These results could be explained by the fact that children and parents had access to expert clinicians and to a multidisciplinary team, and that they had received good care and relevant information

Table 6: The different dimensions of well-being (mean and SD) by gender in the patient group.

Dimensions of well-being	Girls (<i>n</i> = 19)		Boys (<i>n</i> = 12)		95% confidence interval for the mean difference
	Mean	SD	Mean	SD	
Alertness	64.3	13.3	69.1	13.8	-15.0 to 5.4
Self-esteem	62.1	12.7	68.3	10.3	-16.0 to 1.8
Mood	71.8	15.2	76.5	10.9	-15.0 to 5.7
Elation	49.9	13.2	52.2	10.3	-11.5 to 6.9
Stability	69.8	15.6	77.6	11.1	-18.4 to 2.8
Vitality	57.4	16.0	68.8	13.8	-22.6 to -0.2 ^a
Total score	62.5	10.6	68.7	6.8	-13.2 to 0.8

^a $P < 0.05$ for gender difference on vitality.

Table 7: Bivariate correlations between the dimensions of well-being in the patient group (*n* = 31).

	I	II	III	IV	V	VI
I Alertness	—	0.55 ^a	0.61 ^a	0.26	0.52 ^a	0.46 ^a
II Self-esteem	—	—	0.35	0.20	0.38 ^a	0.45 ^a
III Mood	—	—	—	0.40 ^a	0.73 ^a	0.23
IV Elation	—	—	—	—	0.50 ^a	0.26
V Stability	—	—	—	—	—	0.18
VI Vitality	—	—	—	—	—	—

^a $P < 0.05$

about the diagnosis, prognosis and treatment (improved medication).

The present data indicate that there were no statistically significant differences between gender on any of the variables except for *vitality*, which was higher in boys. It is worth noting that boys scored higher (i.e. better) than girls with regard to *vitality* and *self-esteem*, while girls had higher scores for *elation*, as reported by Wiklund *et al.*¹⁴. Tibblin *et al.*²⁸ found that women report more problems than men, suggesting that gender might influence scores of QoL questionnaires. Austin *et al.*²⁹ compared QoL in youth with inactive or active epilepsy with that of a similar group with asthma, and found that there was a gender difference related to QoL in the epilepsy sample. Girls with severe epilepsy had more associated problems. A recent study³⁰ compared academic achievement in children with epilepsy or asthma. It was shown that boys with severe epilepsy had more difficulties with academic functioning.

Assessment of children's QoL is an area which has recently become increasingly important in clinical and epidemiological studies³¹. There are different definitions of QoL. One definition suggests a view of life as a combination of external factors, interpersonal relations and internal (psychological) factors. Health-related quality of life (HRQL) implies a limitation and refers to function and well-being when influenced by disease or illness³². HRQL can be used to describe aspects of the impact of disease or illness in individuals. It can also be used to evaluate the impact of individual treatments or programmes of services on populations. Finally, HRQL can be used to predict the future status of people with an illness or condition of disturbed

health³³. The need to assess HRQL, including well-being of children with epilepsy, is obvious¹³.

A large cross-cultural study of QoL of people with epilepsy in 15 European countries focused on differences in QoL associated with seizure severity, as measured by seizure frequency and type. Seizure frequency was shown to be a key factor in influencing patients' perception of the impact and stigma of their condition. Reducing side-effects and achieving better control of seizures are essential to improve the quality of life of people with epilepsy, as is reducing the stigma and handicap associated with it³⁴.

Epidemiological studies have shown that seizures will be well controlled by antiepileptic drug (AED) treatment in 70–80 percent of individuals who develop epilepsy³⁵ and this study indicates that epilepsy does not profoundly diminish the quality of everyday life in this group of patients. In the remaining 20–30 percent whose seizures are chronic and intractable, the prospect may be less optimistic^{36,37}.

For the group of children with controlled epilepsy aged from 9 to 13 years in the present study, the results show that they did not differ significantly from the age-matched control group, which is considered to be representative of healthy children of the same ages. Whether the conditions are different for children with intractable epilepsy remains to be investigated.

Austin *et al.*³⁸ found that children with epilepsy had a more limited quality of life in the psychological, social and school domains. In contrast, children with asthma had a more compromised quality of life in the physical domain. Their findings suggest that attention simply to seizure control in the clinical setting will not address the full range of quality of life problems of children with epilepsy. They suggest that longitudinal research is made to determine whether children who are no longer being actively treated for their conditions show subsequent improvement in quality of life.

Physical activity does not increase seizure frequency and children should be encouraged to be more physically active³⁹. Physiotherapy is known to have a positive effect on children with developmental coordination disorders⁴⁰ and it should be provided to children with epilepsy as early as possible, when motor and sensory impairments and disabilities are found¹⁶. It would be interesting to investigate if motor and sensory function, as well as well-being, would improve after physiotherapy intervention in these children.

Health-outcome research in relation to well-being and QoL instruments is an evolving field, not only conceptually but also methodologically. The relationship between the severity of epilepsy and its impact on quality of life is complex and may be mediated by a number of different factors, including patients' own perceptions of themselves, their conditions and its treatment^{41–43}.

CONCLUSION

According to the results of this study, children with controlled epilepsy feel as well as children of a control population. It seems likely that assessment of well-being generates information that can provide a basis for improvements in the medical and psychological care of children with epilepsy.

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