

DEVELOPMENT AND VALIDATION OF A HEALTH RELATED QUALITY OF LIFE QUESTIONNAIRE FOR BRAZILIAN CHILDREN WITH EPILEPSY

Preliminary findings

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ABSTRACT - Purpose: To construct a multidimensional questionnaire that analyses the epileptic child quality of life from the parental point of view. **Method:** The pilot questionnaire was composed of 157 questions distributed in several dimensions. Fifty-one epileptic children's parents answered the questionnaire. The instrument was tested in its diverse properties: frequency of endorsement, homogeneity (Cronbach alpha), criterion and face validity, and later it was reduced. **Results:** Endorsement frequency excluded 65 questions that did not attain a minimum of 5% response per item. Cronbach alpha was as follows: physical (0.93), psychological (0.91), social (0.91), familiar (0.70), cognitive (0.92), medical (0.30) and economical (0.37). Patient groups, in relation to seizure control, significantly differed only in physical domain and total score, although there was a trend to differences in other domains. The final questionnaire (QVCE50) has 50 items, with good homogeneity in the physical, psychological and cognitive domains. **Conclusion:** QVCE-50 is a promising Brazilian HRQL questionnaire for children with epilepsy. It needs to be applied in a larger population to confirm its psychometric properties.

KEY WORDS: quality of life, epilepsy, childhood, adolescence.

Construção e validação de um questionário de qualidade de vida relacionada à saúde para crianças brasileiras com epilepsia: resultados preliminares

RESUMO - Objetivo: Construir um questionário multidimensional analisando a qualidade de vida da criança com epilepsia do ponto de vista dos responsáveis. **Método:** O questionário piloto foi composto de 157 itens distribuídos em várias dimensões. Cinquenta e um responsáveis de crianças com epilepsia responderam ao questionário. O instrumento foi testado em suas diversas propriedades frequência de endosso, homogeneidade (alfa de Cronbach), validade de critério e aparência, sendo posteriormente reduzido. **Resultados:** A frequência de endosso excluiu 65 questões que não atingiram um mínimo de 5% de respostas por item. O alfa de Cronbach foi: domínio físico (0,93), psicológico (0,91), social (0,91), familiar (0,70), cognitivo (0,92), médico (0,30) e econômico (0,37). Os grupos de pacientes (de acordo com o controle de crises) diferiram significativamente apenas no domínio físico e no escore total, embora seja percebida uma tendência à diferença nos demais domínios. O questionário final (QVCE50) tem 50 itens, com boa homogeneidade nos domínios físico, psicológico e cognitivo. **Conclusão:** O QVCE-50 é um questionário de qualidade de vida relacionada à saúde promissor. Há necessidade de aplicá-los a uma população maior a fim de testar suas características psicométricas.

PALAVRAS-CHAVE: qualidade de vida, epilepsia, criança, adolescente.

Any chronic disease poses threats to a child's physical, psychological, social and cognitive development^{1,2}. Epilepsy seems to affect children more than other chronic diseases such as asthma³. Some aspects that add to poor quality of life in epilepsy include disease characteristics (etiology, seizure fre-

quency, collateral effects of anti epileptic drugs or surgery, risk of accidents), psychological consequences (personal and parental concerns, feelings of guilt and rejection, personality development) social insertion (limitations at work and leisure time) and educational achievement (school performance and

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vocational issues)⁴. It is essential that a modern epilepsy approach recognize the influence of these factors on disease control and children's well being. Successful treatment should not be measured only by seizure control, but also by quality of life improvement^{4,5}. Quality of life has been deeply studied in the epilepsy field. Health related quality of life (HRQL) is a multidimensional construct that deals with one person's perceptions about disease's burden at several dimensions of life (physical, psychosocial, cognitive, work).

There are many HRQL instruments for epileptic adults, with defined validity and reliability. Some of them have already been translated into the Portuguese language⁵⁻⁹. Generic and qualitative measures have also been published¹⁰⁻¹⁴. These instruments can be applied on research (population studies, drug trials and clinical outcome after drug or surgical treatment) and clinical settings. There is comparably limited research dealing with HRQL of epileptic children. Methodological issues are a particular limitation since parental perception, the child's own opinion and developmental changes are to be dealt with¹⁵. There are a number of studies of individual aspects of HRQL in epileptic children¹⁶⁻²³ but few with a multidimensional approach²²⁻²⁷. Only Sabaz and col.²² describe methodological aspects of validity

and reliability. Their study is limited to refractory epilepsy. Because of the high prevalence of epilepsy in children, it's important to make specific instruments for them, especially in developing countries where living with epilepsy is an additional problem that limits one's growing and social development.

The aims of this study were: 1. To develop a Portuguese instrument that evaluates HRQL of the epileptic child in its physical, psychological, social/familiar and cognitive/educational domains from the familiar point of view. 2. To define instrument validity.

METHOD

Development of the pilot questionnaire – The construct utilized was "health related quality of life". It implies in asking the patient (at this case, the family) about the perceived state of well being and the impact of the disease (epilepsy) at several domains. We emphasized the aspects of quality of life that can be modified by medical decision or health policies, not including social (structural, economical aspects) and environmental issues that, although pertinent to the WHO conceptualization, are less manageable by clinical action¹ and that refers to the entire population and not specifically to the patient. In spite of this first consideration, we decided to include, experimentally, an economic and a medical assistance domain (doctor-patient relationship) due to the socioeconomic characteristics of Brazil. The

Appendix 1. Pilot questionnaire content.

Physical domain

Children care
Leisure time
Sports
Restrictions to physical activity
Self care
Transport utilization
Accidents
Physical pain
Energy and vitality
Sleep
Side effects of antiepileptic drugs
Seizure frequency perception
Seizure characteristics
Help at seizure time
Necessity of urgent medical visits or hospitalization

Psychological domain

Feelings
Fear of accident or death
Behavior

Social domain

Social prejudice
Restrictions to social activities
Social knowledge about disease

Familiar domain

Relationships
Shame because of the disease
Guilt because of disease
Limitations to family life
Job limitations and family plans restrictions
Family happiness

Cognitive / educational domain

School achievement, attendance and behavior
Cognition (memory, attention, comprehension, language, reading, arithmetic)

Medical assistance domain

Doctor-patient relationship

Economical domain

Economical aspects (access to medications and attendance to medical visit)

General domain

Perception of health and quality of life
Future expectations

questionnaire was answered by the person responsible for the child. Items have four possible answers, scored one to four. Domains were equally weighted by means of per cent scores. Items have been built from previous scales consultation (adaptation and translation with authorization), bibliographical revision of theoretical basis of the domains and the authors' clinical experience. Appendix shows item description utilized^{7,16-19,22,24,27-35}. Items were critically reviewed in terms of complexity, ambiguity, jargons, moral judgments and negative feelings. Some items, then, have been modified or discharted. The content and face validity have been taken into consideration. The pilot questionnaire contained 157 questions, divided into physical domain (47), psychological domain (51), social (11) and familiar (13) domains, cognitive/educational (28) domain, medical assistance (2) and economic (2) domains, plus 3 general questions about quality of life. The questionnaire ended with a quality of life scale scored 0 to 10, and a space for free observations.

Pilot questionnaire application – The pilot sample included 51 epileptic children families consecutively seen at the Neuropediatrics services of the Institute of Pediatrics/ Universidade Federal do Rio de Janeiro (42 - 82.3%)

and Faculdade de Medicina de Petrópolis (9 - 17.7%). This study was approved by the Ethical Committee of IPP-MG/UFRJ, process 23/01. The eligibility criteria were: age between six and 16 years-old; epilepsy diagnosis according to ILAE^{36,37}; minimum of 6 months of disease and regular medical assistance, school attendance and direct caregiver present at the moment of the interview. Serious physical disability or mental retardation³⁸ were excluded.

Pilot questionnaire analysis and reduction – We applied the frequency of endorsement (minimum of 0.05) as an indicative of item importance, and the Cronbach's alpha (minimum of 0.70), and the total-item correlation (minimum of 0.20), as domain homogeneity indicators³⁹. After items had been discarded by these criteria, alpha in the psychological and cognitive/educational domains was still high, allowing domain reduction by qualitative means (less intelligible or similar items). The final result was a 50-item questionnaire (QVCE-50: "quality of life of the epileptic child" in Portuguese - 50 items), with the following distribution in the domains: physical (14), psychological (37), social/familiar (7), cognitive/educational (23). The criteria validity was also tested by comparing per cent scores of three different seizure groups

Table 1. Per cent scores and seizure control - Pilot questionnaire.

| Score (%) | Total | Controlled | Few seizures | Intractable | P |
|---------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|------|
| Physical | 83.5 CI 80.34 / 86.66 SD 11.5 | 88.9 CI 84.90 / 92.90 SD 8.9 | 81.6 CI 77.45 / 85.75 SD 10.8 | 74.1 CI 61.94 / 86.26 SD 15.2 | 0.01 |
| Psychological | 76.8 CI 73.73 / 79.87 SD 11.2 | 78.9 CI 73.91 / 83.89 SD 11.1 | 76.4 CI 72.29 / 80.51 SD 10.7 | 73.3 CI 61.94 / 84.66 SD 14.2 | 0.54 |
| Social | 85.7 CI 80.87 / 90.53 SD 17.6 | 85.6 CI 77.69 / 93.51 SD 17.6 | 89.1 CI 83.56 / 94.64 SD 14.4 | 71.2 CI 50.88 / 91.52 SD 25.4 | 0.08 |
| Familiar | 84.6 CI 80.84 / 88.36 SD 13.7 | 82.7 CI 74.79 / 90.61 SD 17.6 | 87.3 CI 83.26 / 91.34 SD 10.5 | 78.8 CI 70.08 / 87.52 SD 10.9 | 0.3 |
| Educational | 76.9 CI 72.70 / 81.10 SD 15.3 | 81.5 CI 74.53 / 88.47 SD 15.5 | 75.7 CI 69.93 / 81.47 SD 15.0 | 67.4 CI 57.24 / 77.56 SD 12.7 | 0.12 |
| Medical | 96.6 CI 94.13 / 99.07 SD 9.0 | 97.4 CI 93.40 / 100 SD 8.9 | 97.6 CI 95.29 / 99.91 SD 6.0 | 89.5 CI 76.22 / 100.0 SD 16.6 | 0.12 |
| Economical | 68.4 CI 61.57 / 75.23 SD 24.9 | 73.7 CI 62.95 / 84.45 SD 23.9 | 67.3 CI 57.88 / 76.72 SD 24.5 | 56.2 CI 32.84 / 79.56 SD 29.2 | 0.31 |
| General | 77.7 CI 72.84 / 82.56 SD 17.7 | 80.3 CI 70.36 / 90.24 SD 22.1 | 78.1 CI 73.37 / 82.83 SD 12.3 | 68.0 CI 50.40 / 85.60 SD 22.0 | 0.33 |
| Total | 80.5 CI 77.81 / 83.19 SD 9.8 | 83.7 CI 80.06 / 87.34 SD 8.1 | 80.0 CI 76.31 / 83.69 SD 9.6 | 72.4 CI 63.12 / 81.68 SD 11.6 | 0.04 |

CI, confidence interval; SD, standard deviation.

Table 2. Per cent scores and seizure control - QVCE-50.

| Score (%) | Total | Control | Few seizures | Intractable | P |
|-----------------------|--------------------------------------|--------------------------------------|--------------------------------------|--------------------------------------|-----------|
| Physical | 76.3 CI 67.59 / 85.01 SD 14.05 | 89.2 CI 87.85 / 90.55 SD 2.18 | 69.4 CI 63.75 / 75.05 SD 10.4 | 56.9 CI 42.29 / 70.51 SD 9.82 | p < 0.001 |
| Psychological | 77.2 CI 70.69 / 83.71 SD 10.5 | 78.0 CI 71.62 / 84.38 SD 10.30 | 77.1 CI 70.94 / 83.26 SD 11.34 | 73.6 CI 57.27 / 89.93 SD 11.78 | 0.87 |
| Social/familiar | 85.6 CI 78.77 / 92.43 SD 11.02 | 90.0 CI 85.13 / 94.87 SD 7.86 | 81.3 CI 74.53 / 88.07 SD 12.46 | 91.07 CI 87.58 / 94.56 SD 2.52 | 0.12 |
| Cognitive-Educational | 78.2 CI 68.27 / 88.13 SD 16.02 | 84.7 CI 78.32 / 91.08 SD 10.30 | 75.1 CI 64.83 / 85.37 SD 18.90 | 66.4 CI 52.62 / 80.18 SD 9.94 | 0.20 |
| Total | 78.6 CI 72.36 / 84.84 SD 10.06 | 83.8 CI 78.74 / 88.86 SD 8.16 | 75.7 CI 70.07 / 81.33 SD 10.36 | 70.7 CI 62.37 / 79.03 SD 6.01 | 0.07 |

CI, confidence interval; SD, standard deviation.

Table 3. Reduction of the pilot questionnaire.

| Domains | Remaining items | Conbrach's alpha | More items excluded | Total end | Final Conbrach's alpha |
|-----------------------|-----------------|------------------|---------------------|-----------|------------------------|
| Physical | 14 | 0.75 | 5* | 9 | 0.75 |
| Psychological | 37 | 0.90 | 19** | 18 | 0.86 |
| Social/ familiar | 7 | 0.60 | - | 7 | 0.60 |
| Cognitive/educational | 23 | 0.93 | 7*** | 16 | 0.88 |
| Total | 81 | - | 19 | 50 | - |

* Items about side effects were grouped in a single question about side effect frequency. ** Items excluded were those about similar feelings, negative value or of difficult understanding. *** Items that specified different levels of attention, memory and understanding were reduced to single questions, since parents didn't understand them.

(seizurefree, few seizures - less than 10 per year, uncontrolled seizures), searching for significant decrease in HRQL with worse seizure control (p<0.05).

Final questionnaire application – QVCE-50 was sent by mail to 31 of the 51 original families who had up to date addresses. Only 25 questionnaires were sent back. The same member of the family answered the second questionnaire.

Validity of the final questionnaire – Cronbach's alpha, total-item correlation and criterion validity were applied to QVCE-50.

RESULTS

Age of patients varied from six to 16 years old (mean 10 ± 3 years), with 27 females (52.9%) and 24 males (47.1%). Twenty-one were Caucasians (41.2%), 16 blacks (31.4%) and 14 interracial (27.5%). Forty-nine patients (94.2%) were from low income. Four (7.8%) patients had slight mental retardation and 2 (3.9%), discrete hemiparesis. Nineteen questionnaires (37.3%) were dictated, and 32 (62.7%)

were self-answered. The responders were the mother (43-84.3%), father (4-7.8%), grandmother (3-5.9%) or both parents (1-2.0%). All children and adolescents were regularly going to school.

Epilepsy duration was six years in mean. Twenty (39.3%) had focal seizures, 6 (11.7%) focal seizures with secondary generalization and 25 (50%) primary generalized seizures. Thirty-five (68.6%) of the epilepsies were idiopathic. Nineteen (37.3%) children were seizure free, 26 (51%) had few seizures and six (11.8%) intractable seizures. Forty-five patients were in monotherapy and 2 (3.9%), temporarily without drugs.

Percent scores of the pilot and final questionnaires are shown at Table 1 and 2, as well as score differences between groups of seizure control. Statistical analysis and the reduction process are shown in Table 3.

DISCUSSION

Development and application of the pilot questionnaire – Developing an HRQL instrument implies

attaining several stages of quality, allowing its validity in describing and quantifying the biopsychosocial well being of a given population⁴. The instrument must be broad and specific to the disease; even though generic instruments have their value. It must be quantitative, permitting standard application and reliability. The construct validity of a questionnaire depends on the exact definition of quality of life used. We opted for the health related quality of life definition, because it is related to aspects in which health professionals may interfere. The trial of including economical and assistance aspects has not proven to be efficacious (low frequency of endorsement). We decided to abandon these items in the final questionnaire, although they are important as far as public health is concerned.

Deciding for the parent view is also controversial. We took into consideration that the perception of health and disease matures with age and is different across stages of life^{16,40-42}. It would be necessary a different questionnaire for each age, but that would be difficult at this stage of instrument development. It seems that biases are more present when proxies are answering for adult patients. Parents give more adequate responses about functional characteristics than subjective ones, like personal feelings and familiar dynamics⁴³. This may be a possible explanation why the physical domain is the only one to attain criteria validity, when comparing different levels of seizure control.

The number of patients chosen were according to literature orientation about samples for questionnaire construction³⁹. We had difficulty increasing samples because of the rigid criteria selection, since the tertiary services we performed had a significant number of intractable epilepsy patients with mental retardation and motor handicaps. Patients without these problems are generally idiopathic epilepsy ones. This artificial manipulation was necessary in the questionnaire construction. In practice, a physician must take into account all patients problems concerning quality of life.

The total number of items must be a limiting factor in the quality of the responses. In the initial stage, it was essential to have the greatest number of items possible, attaining content validity. We revised all questionnaires for missed answers. Few parents answered the free spaces, probably because of exhaustion after answering the objective part. Another important factor was the necessity of simplifying the content of questions because of the low

scholarship of parents. Quality of life questionnaires suffer transcultural variations and a simple translation is not always appropriate³⁹. The richness of details in some questions of original instruments was lost in order to make them more understandable to a poor educated population. This instrument is valid for public health services of neuropsychiatry in developing countries where Portuguese is spoken. Its use with populations of better socio-economical conditions must underestimate important aspects of quality of life, especially in the psychological domain.

Questionnaire reduction – It was already expected a great exclusion of items, since the pilot instrument covered all possibilities within each domain, making them extensive. The fact that many questions of validated instruments were excluded is understandable. Translation, simplification and utilization out of the original domain context turns the items into new ones, with new psychometric properties that should be tested³⁹ again. The frequency of endorsement was the statistical technique that excluded the greater number of items. The low number of intractable epilepsy patients must turned answers to a more positive direction. In discarding these questions, it was intended to make the instrument a more discriminative one. There was a significant difference between groups of seizure control in the physical domain and total score (Tables 1 and 2). The other domains showed a trend to difference, which could be proved with a large sample. Information of the total score is dubious, since mixing different domains information makes little sense. Homogeneity of pilot domains was good, as measured by Cronbach's alpha and total-item correlation (Table 3). Reduction affected social and familiar domain homogeneity. We tried to mix social and familiar items in a unique domain, but alpha continued below 0,70. The excellent alpha of the psychological and cognitive domains allowed us to lower question numbers by qualitative means, making the final questionnaire shorter.

The final instrument (QVCE-50) – QVCE-50 maintained good homogeneity in the same domains, and criteria validity was attainable only in the physical domain. The lower number of respondents did not permit validity conclusions with the sample. It will be necessary a new and bigger sample to retest criteria validity and to test reliability.

In conclusion, QVCE-50 is a promising Brazilian

HRQL questionnaire for children with epilepsy. This new perception of health and disease opens a perspective of a more efficacious and individualized treatment for epileptic children. The next step is to retest QVCE-50 psychometric properties with a bigger sample. It may be necessary to rebuild the social and familiar item. We intend to test reliability with test-retest. Other functions of the instrument that must be analyzed are changes in quality of life in time and specific treatments.

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