

RESEARCH ARTICLE

# Psychometric Properties of the Autoquestionnaire Qualité De Vie Enfant Imagé (AUQEI) Applied to Children with Cerebral Palsy

Wener Barbosa-Resende<sup>1\*</sup>, Viviane de Oliveira Rangel<sup>2</sup>, Ana Claudia Frontarolli<sup>3</sup>, Renata R. Hoffman Araújo<sup>4</sup>, Carlos Henrique Martins da Silva<sup>5</sup>, Rogério de Melo Costa Pinto<sup>1,6</sup>, Nívea de Macedo Oliveira Moraes<sup>5</sup>

**1** Graduate Program in Health Sciences, Faculty of Medicine, Federal University of Uberlândia, Uberlândia, Minas Gerais, Brazil, **2** Faculty of Medicine, Federal University of Uberlândia, Uberlândia, Minas Gerais, Brazil, **3** Physical Therapy and Specialty Center Unimed, Uberlândia, Minas Gerais, Brazil, **4** Association for Assistance to Disabled Children, Uberlândia, Minas Gerais, Brazil, **5** Department of Pediatrics, Graduate Program in Health Sciences, Faculty of Medicine, Federal University of Uberlândia, Uberlândia, Minas Gerais, Brazil, **6** Center of Exact Sciences and Technology, Faculty of Mathematics, Uberlândia, Minas Gerais, Brazil

\* [wener\\_educa@hotmail.com](mailto:wener_educa@hotmail.com)



## Abstract

### Background

Quality of life (QL) assessments of children with incapacitating diseases, such as cerebral palsy (CP), have often been conducted with the help of the representatives of a child, making QL assessment more subjective. The Autoquestionnaire Qualité de Vie Enfant Imagé (AUQEI) is a QL assessment designed for children to self-report—it uses images to facilitate the reporting process.

### Objective

evaluate the psychometric properties of AUQEI when responses are given by children with CP.

### Findings

Children aged 4 to 12 years (45 with CP and 45 healthy children) gave responses to the questionnaire. The data quality, reliability and validity were assessed. The data loss rate ranged from 8.8% to 46.7%, and was highest for the “autonomy” factor. No floor or ceiling effect was detected. The success rate for reliability of the internal consistency of the items was less than 80% for the “autonomy” factor. Cronbach’s alpha coefficient was 0.71 for the instrument and less than 0.5 for the factors. All the factors had a success rate of greater than 80% for the discriminating validity of the items. The factors did not have correlations between each other, thus indicating adequate discriminating validity. Convergent validity was tested and a significant correlation was demonstrated only between the AUQEI “functioning” factor and the Child Health Questionnaire—50-Item (CHQ-PF50) physical summary

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score ( $r = 0.31$ ,  $p = 0.042$ ). The AUQEI scores did not have correlations with the gross motor function scores ( $p > 0.05$ ) as expected for divergent validity. Regarding construct validity, the total AUQEI score obtained by the CP group was lower (median: 47.3) than that of the healthy group (median: 51.0) ( $p < 0.01$ ).

## Conclusion

The AUQEI was shown to be a reliable and valid instrument for assessing children with CP when the total score was used. Convergent validity should continue to be tested in future studies.

## Background

The assessment of quality of life (QL) in children with cerebral palsy (CP) is important because this population has reduced activity levels and limited participation due to disorders of movement, posture, sensation, perception, cognition and communication imposed by the disease, which can lead to negative repercussions in QL [1], [2]. According to the World Health Organization Quality of Life (WHOQOL), QL is defined as “the individual’s perception of their position in life, in the cultural context and value systems in which they live and in relation to their goals, expectations, standards and concerns” [3].

The QL studies among children with incapacitating diseases such as CP [4] present limitations with regard to responses obtained directly from the patients and there is often a need to rely on a representative [5]–[7]. Although this means of obtaining data is indispensable in situations of greater cognitive impairment, it makes QL assessments more subjective [8]. Because of differences of perspective between children and their parents [9], efforts towards refining and placing value on measurements that evaluate children’s own perceptions have increasingly been made. Some generic instruments such as the Pediatric Quality of Life Inventory (PedsQL) and the European generic Health-related Quality of Life questionnaire (KIDSCREEN) [10], [11] and specific instruments such as the PedsQLcerebral palsy module and the Cerebral Palsy Quality of Life Questionnaire for Children (CPQOL-Child) [10], [12], have been validated to be answered by children with CP themselves.

A systematic review evaluated the psychometric properties and clinical utility of all condition-specific outcome measures used to assess QL in school-aged children with CP, and the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) and the CPQOL-Child demonstrated the strongest psychometric properties and the greatest clinical utility [2]. Another study compared the conceptual differences, internal consistency, and validity of three QL questionnaires. Conceptually and psychometrically, KIDSCREEN-10 and CPQOL-Child performed more strongly than the Child Health Questionnaire (CHQ) for children with CP. The choice between these instruments will depend on the questions posed and outcomes sought by the researcher or clinician [1]. But it is important to consider the psychometric properties of the instruments and if it is applied directly to the child or to a proxy.

The AutoquestionnaireQualité de Vie Enfant Imagé(AUQEI) is a generic QL instrument that has the advantage of facility of use—it utilizes the support of images so that children can better express their comprehension of the questions and their satisfaction regarding family factors, social factors, activities, health, body functions and separation. This instrument is easy to apply and can be answered from the age of four years onwards [13], [14]. It has also been applied to children with CP, although its psychometric properties have not been tested for this

population[15]-[17]. Hence, the objective of the present study was to evaluate the psychometric properties of AUQEI when responses are given by children with CP.

## Methods

### Participants and procedure

Over a six-month period, children with CP aged 4 to 12 years who frequently visited a pediatric rehabilitation unit (Association for Assistance to Disabled Children-Minas Gerais/AADC-MG) were invited to participate in a cross-sectional study. Informed consent was obtained in writing from parents, caregivers or guardians of the children who participated in the survey. Children with cognitive difficulty as measured using the Wechsler Intelligence Scale for Children, Third Edition(WISC-III), were excluded[18]. The healthy group was formed by children of the same age group without chronic diseases.

The patients were evaluated by a neuropsychiatrist to confirm the diagnosis of CP and the clinical data; by a physiotherapist to evaluate physical functioning (Gross Motor Function Measure—GMFM, and Gross Motor Function Classification System—GMFCS)[19], [20]; and by a psychologist to make a cognitive assessment (WISC-III)[18].

The children with CP were classified according to the most dominant clinical characteristics and by anatomic distribution of the lesion. In accordance with changes of muscle tone and movement, the children were classified into the following types: spastic (presence of weakness, hypertonia, hyperreflexia, clonus and plantar cutaneous reflex in extension—positive Babinski, caused by injury to the pyramidal system)[21], [22]; dyskinetic (evident abnormal movements, caused by inadequate regulation of coordination and muscle tone, includes rigidity, chorea, choreoathetosis, athetosis and dystonia, occasioned by a lesion of the extrapyramidal system) [23], [21]; and ataxic (disturbance of coordination of voluntary movements because of dyssynergia, caused by a dysfunction in the cerebellar)[23], [24]. And according to the anatomical distribution, the patients were divided into the following categories: quadriplegia (involves all four limbs and trunk)[21]; diplegia (lower limbs are affected more severely than the upper limbs)[21]; and hemiplegia (impairment of a hemibody with more severe involvement of the upper limbs than the lower limbs, in general)[21]. Intellectual disabilities are present in almost all cases of quadriplegia in the literature[21].

Social, demographic and educational level data were obtained from caregivers. The children were invited to answer the AUQEI (on interview) during an interview with a psychologist. Parents answered two health-related quality of life instruments (HRQL): the initial Brazilian version of the Child Health Questionnaire—50-Item, Parent Complete Short Form (CHQ-PF50)[25], [26] and the Childhood Health Assessment Questionnaire (CHAQ) Brazilian-version[27], [28].

The sample size was estimated from the prevalence data of the CP [29] and from the data published in 2003 by the Center of Studies, Research and Economic-Social Projects (CSRESP) of the Institute of Economics of the Federal University of Uberlândia (UFU) [30].

The population of the study (N) was calculated from the average number of live births in the city of Uberlândia—Minas Gerais—Brazil, in the years of 1998 ( $n = 7885$ ) and 1999 ( $n = 8875$ ) [30], (last two years of birth of inclusion criteria—age), resulting an average of 8380 individuals. The average of live births, between the years 1998–1999, was multiplied by 8, finding a population of 67040 children births between 1991–1999, aged 4–12 years in 2003, (age at which children answered the questionnaire AUQEI). Thus, according to the prevalence of CP (2.18/1000 live births) [29], the size estimated of the population of children with CP live births in Uberlândia—Minas Gerais—Brazil, between the years 1991–1999, was of 146.1472 children.

The sample of the study ( $n$ ) was calculated from the estimated number of the population of children with CP between 4–12 years old, in Uberlândia—Minas Gerais—Brazil—2003, considering a prevalence of 0.218% [29], with the confidence of 99% and error of 1.5% [31].

This study was approved by the institutional review board (AACD-MG 66/2003 and the Federal University Uberlândia-UFU182/03).

## Instrument

### Autoquestionnaire Qualité de Vie Enfant Imagé (AUQEI)

AUQEI is a generic questionnaire for self-assessment of QL [13] that has been translated into Portuguese, culturally adapted and validated for healthy children [14]. It provides a perception of the well-being of children aged 4 to 12 years through using 26 questions with four alternative responses. These responses can be visualized as four images of faces that express different emotional states relating to different domains of the child's life.

The scale is composed of four factors (autonomy, leisure, functioning and family). Questions 6, 7, 9, 12, 14, 20, 22 and 26 are not included in these factors because they represent domains that are separate from the others.

The score for each item ranges from 0 to 3, and higher scores signify better QL. The scale makes it possible to obtain a single score resulting from summing the scores attributed to each item.

## Statistical analysis

Descriptive statistical analysis was used for the demographic and clinical data. The proportion of questionnaires with missing data and floor and ceiling effect were calculated for each factor.

The missing data refer to the proportion of participants who did not complete at least one item of the factor and were considered present when they exceed 20% [32]. The floor and ceiling effect are defined, respectively, as the proportion of patients who had the lowest and highest possible scores for each factor evaluated, and were considered present when they exceed 10% [32].

Internal consistency reliability was verified using Cronbach's alpha coefficient [32].

Item internal consistency and item-discriminant validity were assessed and considered satisfactory if the success rate of the factors was higher than 80% [32].

Discriminant validity was tested by the correlation between all factors. A weak correlation was expected [33].

Divergent validity was determined through the correlation between the AUQEI with the GMFM. A poor correlation was expected [33]. Convergent validity was determined by the correlation of the AUQEI with the CHQ-PF50 physical and psychological summaries and the CHAQ disability index. A significant correlation was expected ( $p < 0,05$ ).

The Spearman correlation coefficient was used for all correlation tests.

To assess construct validity, the Mann-Whitney t-test was used to compare the scores of the CP group with the group of healthy children.

## Results

Out of the 73 patients who were eligible for the study, 28 (38.9%) were excluded because they presented cognitive limitations that made it impossible to answer the questionnaire. Thus, 45 children with CP participated in the study. Their mean age was 8.1 years (SD: 2.2) (Table 1). The healthy group was composed of 45 children with a mean age of 7.5 years (SD: 1.8), of whom 55.6% were female, and 100% of them were in regular school.

**Table 1. Demographic and clinical characteristics of children with cerebral palsy.**

Characteristics	Value (n = 45)
Mean age (years) (SD)	8,1 (2.2)
Male (n) (%)	25 (55.6)
Ethnicity (n) (%)	-
- Caucasian	45 (100)
Classification of CP (n) (%)	-
- spastic	41 (91)
. quadriplegia	2 (4.4)
. diplegia	19 (42.2)
. hemiplegia	20 (44.4)
- extrapyramidal/dyskinetic	1 (2.2)
- ataxic	3 (6.7)
GMFCS (n) (%)	-
- level 1 and 2	31 (68.9)
- level 3	11 (24.4)
- level 4 and 5	3 (6.7)
GMFM—mean of end score (SD)	78,15 (24.58)
Epilepsy (n) (%)	13 (29.5)
Education (n) (%)	-
- not receiving education	0
- receiving special education	5 (11.1)
- receiving regular education	40 (88.9)

SD = standard deviation

CP = Cerebral Palsy

GMFCS = Gross Motor Function Classification System

GMFM = Gross Motor Function Measure

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## Psychometric properties of AUQEI

### Data quality

The data loss rate ranged from 8.8% to 46.7% for the factors (Table 2). Out of the 1170 questions, 94 were not answered. The items with the fewest responses were the following question numbers: 3 (10 patients responded), 14 (20 patients), 17 (16 patients), and 24 (20 patients) (Table 2).

The floor and ceiling effect rates are presented in Table 2.

### Reliability

Regarding the internal consistency of the items, the success rate was less than 80% for the factor “autonomy” (Table 2). Cronbach’s alpha coefficient was 0.71 for the instrument, and it ranged from 0.05 to 0.49 for the factors (Table 2).

### Validity

The success rate for the discriminating validity of the items was greater than 80% for all the factors (Table 2).

In determining correlation between the factors, only the “functioning” factor presented correlations: with family ( $r = 0.47$ ) and with autonomy ( $r = 0.41$ ) ( $p < 0.01$ ).

There was no correlation between the AUQEI scores and the GMFM ( $p > 0.05$ ). The CHQ-PF 50 physical summary score correlated with the AUQEI “functioning” factor ( $r = 0.31$ ;  $p = 0.042$ ) but it did not correlate with the others factors or the total score of the AUQEI ( $p >$

**Table 2. Quality data, reliability and item internal consistency.**

AUQEI-Factors	Data Quality			Reliability		Validity
	Missing data(%)	Floor effects (%)	Ceiling effects (%)	Internal consistency reliability <sup>a</sup>	Item internal consistency <sup>b</sup> (% success)	Item discriminant validity <sup>b</sup> (%success)
Function	8.8	0	0	0.0529	80	95
Family	26.7	0	2.2	0.4872	100	100
Leisure	8.88	0	4.4	0.1416	100	100
Autonomy	46.7	0	0	0.2454	40	90

<sup>a</sup>Cronbach’s alpha coefficient

<sup>b</sup>Spearman’s correlation coefficient

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0.05). There was no correlation between the AUQEI scores and the CHQ-PF 50 psychosocial summary or the CHAQ disability index ( $p > 0.05$ ).

The patients presented lower total AUQEI scores than shown by the healthy group ( $p = 0.001$ ) (Table 3).

### Discussion

The present study indicated that the psychometric properties of AUQEI are adequate for use among children with CP. However, there are some challenges with the “autonomy” factor (high data loss rates and low success rates regarding the internal consistency of the items) and also with the reliability of the internal consistency of the factors that need to be taken into consideration.

The percentage of data loss was high for the “autonomy” factor. The items with the highest frequency of blank responses were those that asked what the child’s feelings were in the following: “when you get marks at school” (item 24; “autonomy” factor), “when you sleep away from home” (item 17; “autonomy” factor), “when you play with your brother or sister” (item 3; “family” factor) and “when you have to stay in the hospital” (item 14). It is possible that most of these questions are not pertinent for children with an incapacitating neurological disease like CP because of the limitations imposed by the disease. None of the items remained unanswered by the healthy children in the present study, and this was also seen in the only study that calculated this rate among children with sickle-cell anemia [34].

The reliability was generally seen to be adequate. Only the factor “autonomy” had results that were lower than desired with regard to the internal consistency of the items. This analysis

**Table 3. AUQEI scores obtained by patients and healthy group, in assessing construct validity.**

Factors	Patients(percentiles 25–75) (n = 45)	Healthy group(percentiles 25–75) (n = 45)	p value*	Effect Size
Function	10.0 (8.5–11.0)	10.0 (8.5–11.0)	0.803	-
Family	10.0 (8.0–10.0)	12.0 (10.0–13.0)	0.000*	0.67
Leisure	6.0 (6.0–7.0)	8.0 (7.0–9.0)	0.000*	1.00
Autonomy	6.0 (5.0–7.5)	8.0 (5.0–9.0)	0.036*	0.50
Total	47.0 (42.0–50.5)	51.0 (48.5–53.0)	0.001*	0.89

\*Mann-Whitney’s test

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had only previously been performed in one study, on children with sickle-cell anemia, which found inadequate values for the “family” and “leisure” factors [34]. The variation in these results reinforces the need for verification of the psychometric properties for each group studied, which should be done before interpreting the results relating to QL [33], [35].

The reliability of the internal consistency was assessed as adequate in the general analysis of the instrument, and was similar to other studies [13], [14], [34], [36]. However, the reliability for each factor was insufficient. Although most authors have only used the total AUQEI score for interpreting the results [15], [14], [34], [37], some authors have taken factor scores into consideration in evaluating QL [38], [39]. For this to be done, Cronbach’s alpha coefficient has to be reapplied to each factor before interpreting the results.

The validity was shown to be generally adequate for the characteristics tested. Only the “functioning” factor had moderate correlations with the “family” and “autonomy” factors in the evaluation of the discriminating validity. Similar results have been found in other studies [14], [38], which may suggest that these factors are measuring similar constructs, or that one aspect of QL may be interfering mutually in one or more factors.

The construct validity was assessed as adequate, since AUQEI enables discrimination between children with CP and healthy children. Other studies using AUQEI have also found differences in the perception of QL when comparing healthy children with children presenting a chronic disease [34], [37], with the exception of one study on autistic children [39].

The convergent validity was shown to be adequate only for the AUQEI “functioning” factor as it had significant correlation with the CHQ-PF 50 physical summary. However, there were no correlations between the AUQEI and the CHAQ disability index or the CHQ-PF 50 psychosocial summary. We believe the results found had occurred, in part, due to limitation of the choice of instrument.

First of all, the CHQ-PF 50 and the CHAQ have been validated to be answered by parents and AUQEI is answered by the children. Some studies have shown that, in general, children and adolescents with CP tend to perceive a minor impact on their QL compared with the perception of their parents [40], [41], there is a low concordance between the perception of children with CP and that of their parents [41], [42]. The judgment of children in this age group and the manner in which they assign values may contain particularities, as there may be crucial differences between what is considered a quality “infant” life from the perspective of an adult and that of the child [43]. Although we know that, at the time the study was conducted, there were no instruments available to the Brazilian population to be answered by children.

The second point about the limitation of the construct validity is due to the nature of the instruments used. AUQEI is a generic QL instrument designated to evaluate what is more important in the point of view of the child, how satisfied he/she is about his/her wishes and hopes. On the other hand, the CHQ-PF 50 is a generic instrument of health-related quality of life (HRQOL) and the CHAQ is a specific instrument to assess HRQOL. HRQOL refers to the satisfaction and well-being of an individual with regard to their physical, psychological, social, economic and spiritual development relative to their state of health [44]. As only the AUQEI “functioning” factor presents a question related to health condition (“how do you feel when you go to a medical evaluation?”), it explains the correlation found with the physical summary of the CHQ-PF 50. But this question does not exactly correspond to the incapacity measured by the CHAQ instrument, so there was no correlation found with the CHAQ.

It was the first time that the convergent validity of AUQEI was tested and it can best be evaluated in future studies using instruments answered by children. Unfortunately, it will be difficult to find an instrument that is as conceptually appropriate to the infant universe as AUQEI.

The low frequencies of floor and ceiling effects suggests that this instrument is adequate for evaluating and discrimination between individuals with different clinical conditions, which in fact was seen in evaluating the construct validity.

The present study should be interpreted taking into consideration possible methodological limitations. The sample size was reduced because more than one third of the eligible patients presented cognitive deficits. However, the proportion of children with CP and intellectual impairment (intelligence quotient [IQ] <70) ranges from 40% to 67.6% in the literature [45]. Our findings were near this range (38.9%). On the other hand, this exclusion enabled an important degree of methodological rigor, given that the application of the instrument has to be conditional on the child's cognitive capacity to comprehend the questions.

According to the literature, the more severe motor impairments are associated with the largest intellectual dysfunctions [46]. The lowest levels of intelligence in children with CP are presented in individuals with higher deficits in gross motor function (GMFCS level-V) and spastic quadriplegia [45]. Thus, the instrument was not applied to and is not capable of evaluating patients with greater degrees of impairment. This is an unbridgeable limitation in QL studies on this population.

This study presents statistical power, since according to the calculation of sample size performed from the prevalence of CP (2.18/1000 live births[29], equal to 0.218%), a confidence level of 99% and a margin of error of 1.5%, the sample size is 45 individuals, which is the number of individuals who completed the questionnaire.

Another methodological aspect to be noted is the fact that the interviews of the children were conducted by a psychologist and we placed a lot of importance on ensuring that the children were comfortable in order to understand and answer the questionnaire. Unfortunately the time expended to complete the questionnaire was not measured.

New validation studies on AUQEI should be conducted, and factorial analysis should be added in order to identify possible problems, particularly with regard to the "autonomy" factor [13].

In conclusion, AUQEI was shown to be a reliable and valid instrument for evaluating children with CP when its total score was used. The reliability was insufficient to use the factors separately. Convergent validity should continue to be tested in future studies.

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## Author Contributions

Conceived and designed the experiments: NMOM CHMS. Performed the experiments: VOR ACF RRHA NMOM. Analyzed the data: WBR RMCP NMOM. Wrote the paper: WBR NMOM.

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