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Validation of the Brazilian Portuguese version of caregiver priorities and child health index of life with disabilities

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ABSTRACT

Aims: To assess the reliability and validity of the caregiver priorities and child health index of life with disabilities (CPCHILD) – Brazilian Portuguese Version (BPV), a measure of health status and well-being of children with cerebral palsy. Methods: After the translation and cross-cultural adaptation of the CPCHILD questionnaire to Brazilian Portuguese previously published, the questionnaire was applied to 104 caregivers of patients with cerebral palsy and was reapplied a second time 2–3 weeks after to measure test-retest reliability (n = 26). The children were classified according to the GMFCS (Gross Motor Function Classification System) from I to V, and demographic data were recorded. Results: The mean age of patients was 12.44±4.04 years. Mean total score on the CPCHILD was 66.68±16.55. The mean of the absolute differences in total scores between first and second questionnaire administration was 0.35±9.03 points (range -1.57 to 2.26). The ICC for the total questionnaire score was 0.959 and ranged from 0.922 to 0.983. Cronbach's α coefficient (internal consistence) was 0.933 and was above 0.80 in all domains of the CPCHILD (range 0.849–0.951), except for the 5th domain (0.472). According to Pearson's correlation coefficient, there was a negative correlation between GMFCS levels and the CPCHILD scores (r= -0.62, p<0.0001). Conclusion: CPCHILD BPV proved to be a reliable and valid instrument to measure the health status and well-being of cerebral palsy children.

Keywords: Assessment, Developmental disabilities, Health-related quality of life, Questionnaire, Validation

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INTRODUCTION

Cerebral palsy is one of the most common causes of chronic disability in childhood with an incidence of 2 to 2.5 per 1,000 live births reported in developed countries [1, 2]. In Brazil, there are not studies reporting this incidence, despite an estimated 30,000 new cases per year [3]. Between 25 and 35% of cerebral palsy children are severely affected, experiencing difficulties with life activities, communication and mobility, what strongly impact their lives and the lives of their caregivers [4–6].

Health-related quality of life (HRQL) is of utmost importance in planning a patient-centered health care system [7]. However, HRQL measurement instruments for children and adolescents with severe developmental disabilities (Gross Motor Function Classification System (GMFCS) functional levels IV and V) are scarce [8]. Previous validated HRQF instruments for children or are generic and do not address adequately non-ambulatory children [9–12], or lack important items for this specific population as comfort, emotions and health status [13, 14]. Therefore, all these instruments are not discriminative outcome measures for this specific population.

In 2006, a disease-specific measure of health status and well-being of children with severe cerebral palsy, the caregiver priorities and child health index of life with disabilities (CPCHILD) was developed specifically for this population, from the perspective of the caregivers. It consists of 37 items over six domains: personal care/activities of daily living; positioning, transferring and mobility; comfort and emotions; communication and social interaction; health and overall quality of life [15]. It has proven to be a reliable, and condition-specific measure. The CPCHILD was considered one of the strongest measures of QoL of children with cerebral palsy in a recent systematic review [16].

Given the increased frequency of multinational and multicultural research projects, there is a tendency worldwide in translate and cultural adapt the same already validated questionnaire to several idioms. The CPCHILD have been recently translated and validated in Korean, German and Dutch [17–19]. The adaptation of health status questionnaires for new countries, cultures or languages requires a unique method to achieve equivalence between the original source and target versions. For this reason, to translate and adapt CPCHILD to Brazilian Portuguese, the currently recommendations of the American Association of Orthopedic Surgeons (AAOS) was used [20–22]. These results were previously published by our group [23]. After translation and cultural adaptation, it is essential to test its reliability and validity. Therefore, the aim of this study was to validate the CPCHILD questionnaire in a Brazilian Portuguese version.

MATERIALS AND METHODS

After the translation and cross-cultural adaptation of the CPCHILD questionnaire to Brazilian Portuguese [23], the final version was applied to 104 caregivers of patients with cerebral palsy, from the outpatient clinics of Botucatu Medical School and Bauru State Hospital, between October 2013 and May 2015. The children were classified according to the GMFCS (Classification System) [8] from I to V, and demographic data were recorded.

The written questionnaire was self-administered, and one of the authors was always nearby to explain any doubts about the questions, if needed. The test-retest reliability was assessed in 26 caregivers, between two and three weeks after initial assessment, according to the next appointment in our hospitals.

This study was approved by the local ethics committee and all parents or caregivers signed the informed consent.

Statistical Analysis

A measure is reliable when repeated administrations of the questionnaire to the same caregiver generates similar responses, provided there has been no change in the condition of the patient during the time elapsed between administrations. Test-retest and inter-rater reliability was estimated by using the intraclass correlation coefficient (ICC) (two-way random effect model, assuming a single measurement and absolute agreement) with 95% confidence interval (CI). ICCs ranging from 0 to 0.20 were considered poor, from 0.21 to 0.40 fair, 0.4 to 0.60 moderate, 0.61 to 0.80 good, and from 0.81 to 1.00 excellent [24].

The method of Bland and Altman was used to assess the magnitude of the measurement error and to calculate limits of agreement [25]. The internal consistency, which is the degree of homogeneity of the item within each subscale, was determined by a Cronbach's α coefficient. Alpha coefficients ≥0.7 for all domains were considered relevant [26].

Construct validity examines the logical relations that should exist between a measure and characteristics of known groups. The CPCHILD dimensions and total scores were compared across GMFCS levels using analysis of variance (ANOVA). According to previous CPCHILD validations in other languages [17–19], we also hypothesized that there would be a negative correlation between GMFCS levels and the CPCHILD scores, analyzed by Pearson's correlation coefficient. The significant level was set at $p<0.05$. Data were analyzed with the software SAS for windows, v.9.3.

RESULTS

A total of 104 parents or caregivers of children with cerebral palsy completed the questionnaire. The mean age of patients at the time of survey was 12.44±4.04 years. Demographic data are given in Table 1. Mean total score on the CPCHILD was 66.68±16.55.

Test-retest reliability was assessed for 26 caregivers. The mean of the absolute differences in total scores between first and second questionnaire administration was 0.35±9.03 points (range -1.57 to 2.26). The ICC for the total questionnaire score was 0.959 and ranged from 0.922 to 0.983 (Table 2). The Bland and Altman plot showed that the measurement error was random and 96.15% of the scores, the limits of agreement, ranged between ±9.2 points of the mean difference (Figure 1). Cronbach's α coefficient (internal consistence) was 0.933 and was above 0.80 in all domains of the CPCHILD (range 0.849–0.951), except 5th domain (0.472) (Table 2).

Table 3 gives the known group validation results. The total score of the CPCHILD was significantly different according to the GMFCS level ($p < 0.0001$). Tukey test showed significant differences in total score between levels I–III and IV–V. The differences between the five GMFCS levels were statistically significant in all domains, except for the overall QoL domain (Table 3, Figure 2).

According to Pearson's correlation coefficient, there was a negative correlation between GMFCS levels and the CPCHILD scores ($r= -0.62$, $p<0.0001$).

In final version of the CPCHILD questionnaire, Section 7 was used to determine whether the items were relevant to individual caregivers and their children [27]. Mean importance rating for all items was 4.18±0.34 with none of the questions rated below 3 (fairly important), what means that none of the items had to be omitted from this Brazilian CPCHILD version.

Table 1: Patients demographics

	Number of patients (%)
Gender (Male/Female)	60/44 (57.69/42.31)
Caregiver Gender (Male/Female)	3/101 (2.88/97.12)
GMFCS level (I/II/III/IV/V)	7/15/14/23/45 (6.73/14.42/13.46/22.12/43.27)

GMFCS: Gross Motor Function Classification System [8]

DISCUSSION

Our study shows that the Brazilian Portuguese version of CPCHILD is a reliable and valid instrument. The test-retest reliability of our CPCHILD Brazilian

Table 2: Reliability of the CPCHILD domain scores and total score

CPCHILD domains	Mean absolute difference (95% CI)	ICC (95% CI)	Cronbach α
Personal care, ADLs	3.66 (-1.09–8.40)	0.970 (0.949–0.985)	0.934
Positioning, transferring, mobility	1.28 (-3.11–5.68)	0.972 (0.952–0.987)	0.951
Comfort, emotions	1.34 (-2.19–4.87)	0.942 (0.901–0.971)	0.867
Communication, social interaction	-4.12 (-9.72–1.48)	0.897 (0.826–0.947)	0.849
Health	-2.05 (-7.64–3.53)	0.770 (0.577–0.888)	0.472
Overall QOL	1.54 (-4.47–7.55)	0.870 (0.710–0.942)	*
Total score	0.35 (-1.57–2.26)	0.959 (0.922–0.983)	0.933

* no Cronbach α since only one item

Table 3: Known groups comparison in CPCHILD-scores in GMFCS groups

CPCHILD domains	GMFCS levels					
	I	II	III	IV	V	p-value
Personal care, ADLs	79.32 (22.9)a	67.32 (22.91)ab	63.21(23.66)ab	51.8 (16.57)b	38.57 (18.32)b	<0.0001
Positioning, transferring, mobility	95.65 (6.49)a	81.7 (18.88)ab	66.94 (20.14)b	45.51 (18.18)c	34.03(17.56)c	<0.0001
Comfort, emotions	84.72 (20.70)ab	90.29 (11.29)ab	96.93 (3.31)a	85.35 (19.63)ab	78.01 (20.29)b	0.019
Communication, social interaction	77.98 (18.95)a	80.25 (16.28)a	79.37 (17.95)a	73.81 (20.00)a	52.78 (16.74)b	<0.0001
Health	81.67 (14.14)ab	82.74 (14.73)a	84.00 (9.7)a	77.69 (19.68)a	68.69 (19.6)b	0.0022
Overall QoL	82.5 (29.15)a	74.12 (16.98)a	80.00 (21.38)a	77.69 (25.5)a	68.15 (20.01)a	0.3748

Means followed by the same letter do not statistically differ by Tukey pos-hoc test ($p<0.05$).

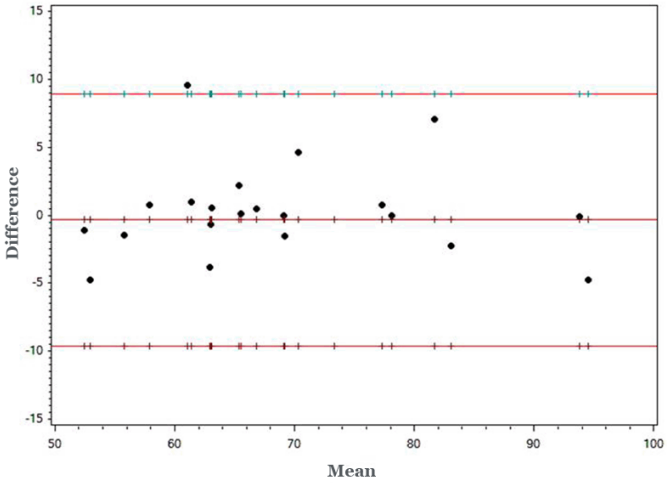

Figure 1: Bland and Altman plot of the test-retest reliability of the total score.

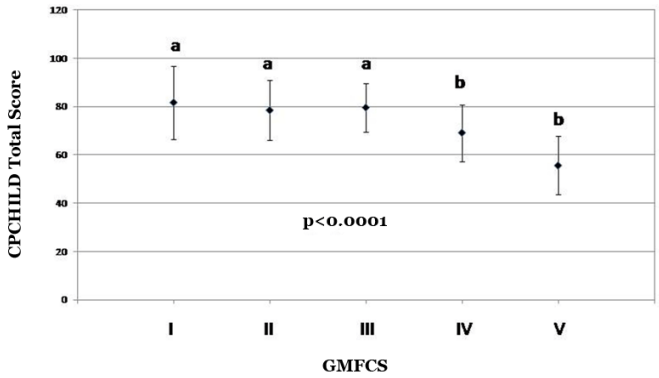

Figure 2: Known groups comparison in CPCHILD-scores total in GMFCS groups.
Mean and standard deviation of the CPCHILD total score according to GMFCS. Means followed by the same letter do not statistically differ by Tukey pos-hoc test ($p<0.05$).

Portuguese version showed excellent results for total and for each domain score, except one, that was in the good range. These results are in agreement with the original version, and above previously published results from Korean, German and Dutch versions [15, 17–19]. The measurement error was random with a small systematic error.

Regarding internal consistency, a Cronbach's α of all domains, except 5th domain, was above 0.8, what is considered relevant. The lower value of Cronbach's α obtained in 5th domain also was found in previously CPCHILD validations [17–19] and can be explained because this domains is composed by only three items.

For known-groups validity the total score of CPCHILD Brazilian Portuguese version was significantly different according to patients' GMFCS level, discriminating levels I-III from IV–V, which is consistent with the original version [15].

There are some limitations of this study, both related to the socioeconomic and educational level of our population. First, the time between the test and retest to establish the reliability, was not possible to be fixed in two or four weeks, as in original, German, Dutch and Korean versions [15, 17–19]. We applied the re-test in the next scheduled appointment, avoiding a visit just for the re-test because of patients' difficulty to come to the appointments. Nevertheless, our test-retest reliability showed good results, with ICC > 0.81, in all except one domain, and the Cronbach α was above 0.7 in all except one domain, what was considered relevant. Second, the questionnaire in our study was self-administered, supervised by one of the authors that were always nearby to explain any doubts about the questions, if needed. Kaplan et al. [28] compared the results of the quality of well-being scale (QWB), between the forms self-administered and interviewer administered and concluded that the results were equivalent. After the explanations made by one of the authors, the answers were possible because of the difficulties of reading interpretation of some of our caregivers.

As in other languages, there is a lack of instruments to measure quality of life in children with moderate to severe impairment. After the validation, future studies using the Brazilian Portuguese version of CPCHILD could be carried out to monitor therapies. The Brazilian Portuguese version of CPCHILD can be downloaded and printed from the Canadian CPCHILD questionnaire website [27].

CONCLUSION

Caregiver priorities and child health index of life with disabilities (CPCHILD) Brazilian Portuguese Version (BPV) proved to be a reliable and valid instrument to measure the health status and well-being of cerebral palsy children.

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Author Contributions
Luiz Antonio Pellegrino – Substantial contributions to conception and design, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published
Erika Veruska Paiva Ortolan – Substantial contributions to conception and design, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

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Guarantor
The corresponding author is the guarantor of submission.

Conflict of Interest
Authors declare no conflict of interest.

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