




# Translation into Brazilian Portuguese and Cross-Cultural Adaptation of the NCCPC-PV for Pain Evaluation of Patients with Intellectual Disability to Communicate\*

## *Tradução para o português brasileiro e adaptação transcultural do NCCPC-PV para avaliação de dor em pacientes com incapacidade intelectual de comunicação*

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### Abstract

**Objective** To perform the translation and cross-cultural adaptation to Brazilian Portuguese of the Non-Communicating Children's Pain Checklist - Postoperative Version (NCCPC-PV) instrument, which assesses acute pain in individuals with severe intellectual disability (ID) who present great cognitive impairment and inability to communicate (CIIC).

**Method** In the adaptation process, the original NCCPC-PV was translated, back-translated, its versions were discussed by a committee of experts, and the resulting tool was tested in 20 health professionals and 20 caregivers of CCIC patients regarding its semantic clarity.

**Results** Data from the present study and its participants were analyzed and their results were described. Thus, "Lista de Verificação de Dor em Crianças Não Comunicantes – Versão Pós-operatória" (Br-NCCPC-PV) was obtained as the final version in Brazilian Portuguese.

**Conclusion** After the present study, the Br-NCCPC-PV was considered adequate for use in the Brazilian population.

### Keywords

- ▶ pain
- ▶ intellectual disability
- ▶ pain measurement

### Resumo

**Objetivo** Realizar a tradução e a adaptação transcultural para o português falado no Brasil do instrumento "Non-Communicating Children's Pain Checklist - Postoperative Version" (NCCPC-PV), destinado a avaliar a dor aguda em indivíduos com deficiência intelectual (DI) grave que apresentam grande comprometimento cognitivo e incapacidade de comunicação (CCIC).

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**Palavras-chave**

- ▶ dor
- ▶ deficiência intelectual
- ▶ medição de dor

**Método** No processo de adaptação utilizado, o NCCPC-PV original foi traduzido, retraduzido, suas versões foram discutidas por um comitê de especialistas, e a ferramenta resultante foi testada em 20 profissionais de saúde e 20 cuidadores de pacientes com CIIC quanto à sua clareza semântica.

**Resultados** Os dados deste estudo e de seus participantes foram analisados, e seus resultados foram descritos. Dessa maneira, obteve-se a Lista de Verificação de Dor em Crianças Não Comunicantes - Versão Pós-operatória (Br-NCCPC-PV) como a versão final para o português falado no Brasil.

**Conclusão** Após este estudo, a Br-NCCPC-PV foi considerada adequada para o uso na população brasileira.

## Introduction

The World Health Organization (WHO) defines intellectual disability (ID) as a state of the mind that has incomplete or interrupted development of skills that contribute to the level of intelligence, such as cognitive, language and social interaction abilities.<sup>1</sup>

The overall prevalence of ID is of 1.03%, and it is almost twice as high in underdeveloped countries compared to high-income countries.<sup>2</sup> Petterson et al<sup>3</sup> found a prevalence of 1% of ID in the general population, but this prevalence is eight times higher in the case of children who had comorbidities at birth. Valk et al<sup>4</sup> revealed that the risk of comorbidities was 2.5 times higher for people with ID than for those without it. Diagnosing these concurrent diseases in patients with ID can be difficult, mainly regarding the most severe cases, due to the lack of appropriate tools and trained professionals to identify such conditions in these individuals with cognitive impairment and inability to communicate (CIIC).<sup>5</sup>

In addition to the comorbidities, patients with CIIC have a reduced ability to express their own health concerns, providing limited insight into their needs. It has been observed that they tend to suffer more accidents often associated with pain and discomfort; however, their pain is not always readily recognized, and, if poorly evaluated, may be administered improperly or go untreated.<sup>6-8</sup> The severity of this situation highlights the need to develop better clinical management strategies, thus leading to a substantial reduction in pain, improved quality of life and better long-term outcomes.<sup>7</sup> Identifying these risk factors for specific pain etiologies can help caregivers and professionals.<sup>9</sup>

These individuals with severe ID are at risk because they often have medical conditions that can cause pain, often requiring procedures, surgical or not, that can also be potentially painful. Many have idiosyncratic behaviors that can mask the expression of pain and are therefore difficult to interpret.<sup>10</sup>

Facing the scarcity of instruments to assess acute pain in patients with CIIC, Breau et al<sup>11</sup> developed and validated the Non-communicating Children's Pain Checklist-Postoperative Version (NCCPC-PV), which quantifies pain following

surgical procedures, or due to other procedures, performed in other environments, that may cause acute pain.

In Brazil, a country where the prevalence of ID is of 0.8%, and where 54.8% of the cases are severe, there are no instruments developed to evaluate acute pain in patients with CIIC, not even for postoperative conditions.<sup>12</sup> Therefore, the present study aims to describe the translation and cross-cultural adaptation of the NCCPC-PV into Brazilian Portuguese, and, once this tool is validated, it may be safely used in various clinical settings, facilitating and optimizing the analgesic management of this specific type of patient.

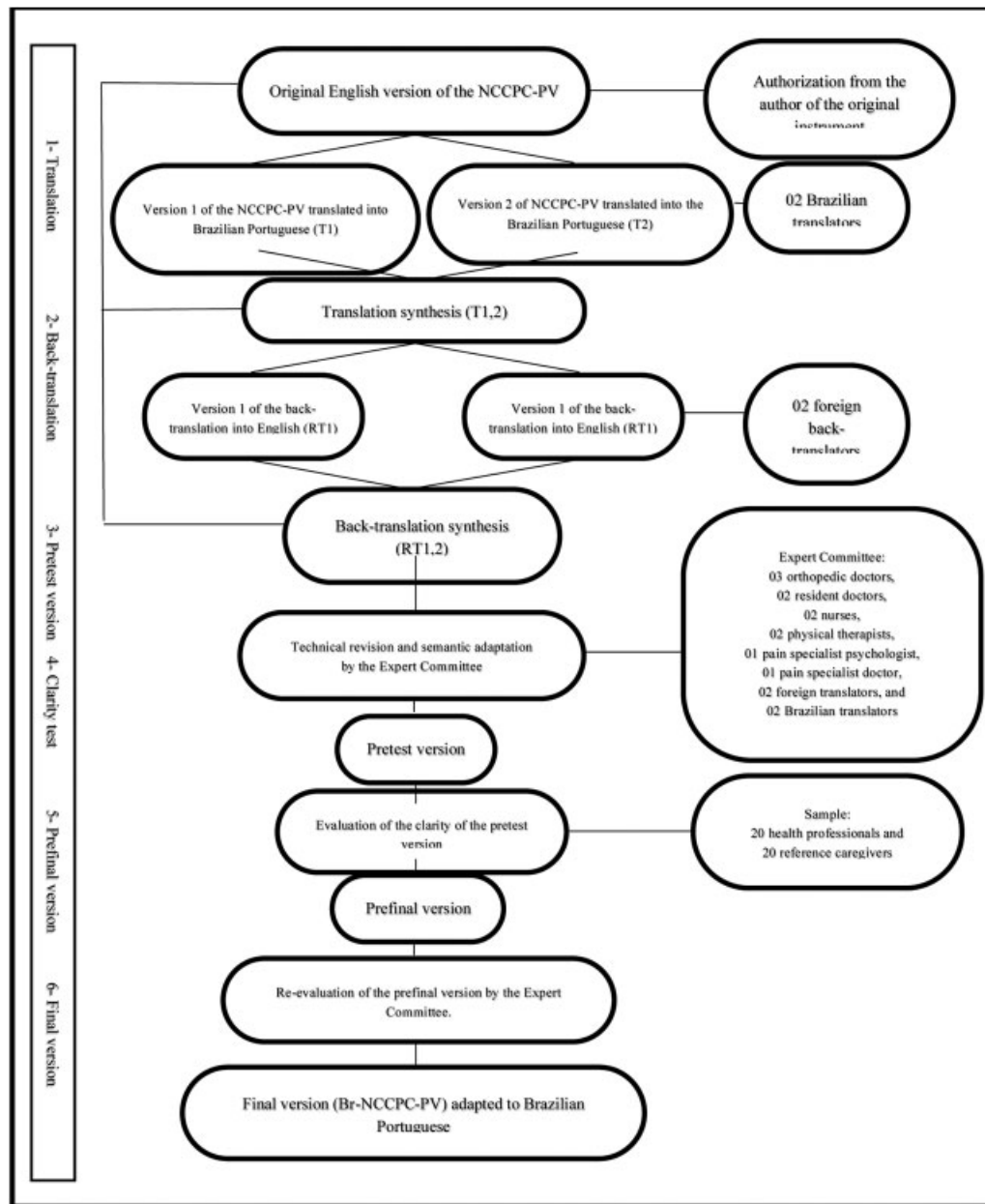
## Methodology

The present was an observational, cross-sectional and descriptive study. The process used (► **Figure 1**) was composed of six stages that followed the guidelines for cross-cultural adaptation of health measurement instruments described by Guillemin et al<sup>12</sup> and modified by Beaton et al.<sup>13</sup>

In the first stage (1), the original instrument in English was translated into Brazilian Portuguese by two independent translators without previous knowledge of the instrument. The translators were two bilingual native Brazilians: one, a physician, and the other, a professional translator, who reached a final consensus version called Translation Synthesis 1,2 (T1,2).

In the second stage (2), the back-translation into English of T1,2 was performed by two translators, who worked autonomously, independently and blinded to the original instrument. The chosen translators had English as their mother tongue, and were not physicians or from any other field in healthcare. After producing their back-translations, called RT1 and RT2, a single, synthesized version, called Back-Translation Synthesis 1,2 (RT1,2), was developed.

During the third stage (3), the original version of the instrument was evaluated, as well as the T1, T2, T1,2, RT1, RT2 and RT1,2 versions, by an expert committee (EC) that produced a prefinal version. This committee was composed of ten interdisciplinary health professionals involved in the care of patients with CIIC, a psychologist with experience in processes of cross-cultural adaptation and validation of



**Fig. 1** Stages of the adaptation process.

quality of life instruments, and by the four translators involved in the previous steps. The goal was to produce the pretest version.

Therefore, in the fourth stage (4), the pretest version was evaluated regarding the clarity of the terms by a sample of the target population, that is, twenty health professionals and twenty caregivers, using a Likert scale with the same five possibilities: unclear; slightly unclear; neither clear nor unclear; clear; and very clear. The data were collected from May 2017 to September 2017. The group of health professionals included professionals who graduated in some field of health, and who had experience caring for children with CIIC, especially in the management of painful situations. The group of caregivers included caregivers of children with CIIC who are assisted at the Pediatric Orthopedics and/or Rehabilitation outpatient clinics of the institutions in-

involved. We considered unable to participate in the sample the caregivers of patients with self-reported abilities to complain of their pain and incapacity, and the caregivers who were unable to understand all of the processes of the research. For epidemiological purposes, we used questions regarding their practice and experience with patients with CIIC.

The prefinal version was defined during the fifth stage (5). Responses from both groups were assessed separately and jointly, and their medians were calculated to identify items lacking clarity. Due to the small sample size, non-parametric statistics were used. The continuous variables were described as medians and interquartile ranges (IQRs). The categorical variables were described as absolute numbers and percentages. Health professionals and caregivers were compared regarding age, sex, education (elementary school,

high school and higher) and origin to assess whether there would be differences in the ability to understand the terms to be adapted. In order to compare the continuous variables, we used the Mann-Whitney test, and the categorical variables were compared by the Fisher exact test or the Chi-squared test. All analyzes were performed using the Statistical Package for the Social Sciences (SPSS, IBM Corp., Armonk, NY, US) software, version 20.0. Values of  $p < 0.05$  were considered statistically significant.

In the sixth stage (6), the items considered less clear were evaluated again only by the caregivers because they obtained lower medians. The six least clear items had a new guiding question: "How could this item become clearer?". Their open answers were compiled, and the suggestions given by the caregivers were re-discussed with the EC, and the final version was obtained.

The translation was previously authorized by the author of the original NCCPC-PV. The present study was approved by the Ethics in Research Committee (CEP), and we followed every ethical principle involved in research on human subjects in Brazil according to resolution 466/2012 of the Brazilian National Health Council. Participation in the study was voluntary, and every participant signed an informed consent form.

## Results

The first step was the translation into Brazilian Portuguese of the original NCCPC-PV. All terms translated (T1, T2 and T1,2 versions) in this stage are described in ►Table 1.

In the second stage, two individual versions of the back translation into English of T1,2 were produced, and then a joint version (RT1,2) was created. ►Table 2 shows all of the independently translated terms, as well as the RT1,2 version.

During the third stage, after the evaluation of all versions by the EC, the pretest version was produced, which was evaluated during the fourth stage by 40 individuals. They analyzed the clarity of the 27 items using the pretest version to evaluate 20 reference patients.

Regarding demographic data, the children were on average 3.09 (IQR = 30–41 months) years old, and cerebral palsy (CP) due to cerebral anoxia was the most common diagnosis among them, with 9 (45%) cases. Microcephaly and Down syndrome also had a higher number of cases: 4 (20%) for each condition. ►Table 3 illustrates the epidemiological characteristics of the reference patients.

All health professionals involved had more than 10 years of training; 14 (70%) had more than 10 years of experience with CIIC patients, and 14 (70%) worked in public hospitals. The data are described in ►Table 4.

In the group of caregivers (►Table 5), we observed that the mother was the primary caregiver of the patient in 17 (85%) cases; most of them were homemakers (15 [75%] cases), and they remained between 12 and 18 hours (7 [35%] cases) or more than 18 hours (11 [55%] cases) per day in the presence of the reference child.

►Table 6 shows the medians of the evaluation of each of the 27 items that compose the prefinal version of the questionnaire.

►Table 7 correlates some characteristics of the caregivers and health professionals. We found that the median age of the health professionals was 10 years older than that of the caregivers. Females were more present, but there was no significant difference between the two groups. A significant difference was found regarding higher education among health professionals.

During the evaluation of the medians and percentiles of the prefinal version, 6 items were identified (items 9, 10, 11, 12, 16 and 24) with medians  $\leq 3.5$ , that is, items that were considered "neither clear nor unclear" according to the Likert scale used. These worse ratings were found only among the caregivers, and for this reason they were chosen for a retest with an open questionnaire to try to make the last improvements and clarity adjustments.

First, item 9 of the pre-final version, "testa franzida" was adjusted by suggestion of the EC to "testa franzida, com o rosto tenso" for better a correlation with pain ratings.

In item 10, the term "squinting of eyes" was translated as "olhos estrábicos", and it was poorly understood. After rediscussing this, we found that the best translation for "squinting of eyes" would be "olhos apertados", and this was the expression chosen for this item in the final version. Another term suggested for "squinting of eyes" was "olhos apertados, fixados, ou assustados."

As for item 11, "virando a boca para baixo, sem sorrir," after a brief discussion, it was altered to "virando a boca para baixo, sem sorrir, fazendo beicinho." Regarding item 12, all suggestions were rejected by the EC, and the item remained as it was already defined in the pretest version.

Item 16 was the one that generated the most discussion: "flácido." Several suggestions were presented by the caregivers, such as "com o músculo mole," "musculature mole," "corpo relaxado" and "molinho." In the end, the suggestion accepted was "flácido, com o corpo relaxado."

Finally, item 24, "sudorese, transpiração" was altered to "sudorese, suando muito, transpirando."

Other changes were also suggested. In item 1, the term "whimpering" was changed to its original translation as "choramingando," and the term "whining" was altered to "reclamando." In item 3, the term "screaming" was changed to "gritando." In item 13, the term "chewing," which had been previously translated as "mordendo," was changed back to "mastigando." In item 20, the final translation was "encolhendo ou recolhendo a parte do corpo que se encontra sensível ao toque." Finally, the term "gasping" in item 26 was translated as "ofegante."

Thus, we developed the final version of the cross-cultural adaptation to Brazilian Portuguese, which was called "Lista de Verificação de Dor em Crianças Não Comunicantes - Versão Pós-Operatória" (Br-NCCPC-PV), and was finally considered adapted.

## Discussion

The NCCPC-PV has attracted the attention of several centers specializing in the treatment of patients with CIIC, due to its easy applicability, as it requires only 10 minutes of observation

**Table 1** Description of the translation stage of the original NCCPC-PV

	Original scale	T1 translation	T2 translation	T1,2 translation
1	Moaning, whining, whimpering (fairly soft)	<i>Gemendo, choramingando, soluçando (levemente)</i>	<i>Gemendo, choramingando, soluçando (levemente)</i>	<i>Gemendo, choramingando, soluçando (levemente)</i>
2	Crying (moderately loud)	<i>Chorando (moderadamente alto)</i>	<i>Chorando (moderadamente alto)</i>	<i>Chorando (moderadamente alto)</i>
4	A specific sound or word for pain (e.g., a word, cry or type of laugh)	<i>Um som ou palavra específica para a dor (p. ex., choro ou tipo de risada)</i>	<i>Um som ou palavra específica para dor (p. ex., uma palavra, grito ou tipo de sorriso)</i>	<i>Um som ou palavra específica para a dor (p. ex., choro ou tipo de risada)</i>
5	Not cooperating, cranky, irritable, unhappy	<i>Não cooperativa, mal-humorada, irritadiça, triste</i>	<i>Não cooperativa, irritadiça, triste</i>	<i>Não cooperativa, mal-humorada, irritadiça, triste</i>
6	Less interaction with others, withdrawn	<i>Menos interativa com os outros, retraída</i>	<i>Menos interativo com outras pessoas, retraído</i>	<i>Menos interativa com os outros, retraída</i>
7	Seeking comfort or physical closeness	<i>Buscando conforto ou proximidade física</i>	<i>Procurando por conforto ou aproximação física</i>	<i>Buscando conforto ou proximidade física</i>
8	Being difficult to distract, not able to satisfy or pacify	<i>Difícil de distrair, incapaz de ser satisfeita ou acalmada</i>	<i>Difícil de distrair, incapaz de ser satisfeita ou acalmada</i>	<i>Difícil de distrair, incapaz de ser satisfeita ou acalmada</i>
9	A furrowed brow	<i>Testa franzida</i>	<i>Sobrancelha enrugada</i>	<i>Testa franzida</i>
10	A change in eyes, including: squinting of eyes, eyes opened wide, eyes frowning	<i>Uma alteração nos olhos, incluindo: olhos estrábicos, olhos arregalados, olhos franzidos</i>	<i>Uma alteração dos olhos, incluindo olhos estrábicos, olhos arregalados, olhos carrancudos</i>	<i>Uma alteração nos olhos, incluindo: olhos estrábicos (apertados), olhos arregalados, olhos franzidos (semiabertos)</i>
11	Turning down of mouth, not smiling	<i>Virando a boca para baixo, sem sorrir</i>	<i>Boca direcionada para baixo, sem sorrir</i>	<i>Virando a boca para baixo, sem sorrir</i>
12	Lips puckering up, tight, pouting, or quivering	<i>Lábios cerrados, apertados, fazendo biquinho ou tremendo</i>	<i>Lábios franzidos, cerrados, amuados ou tremendo</i>	<i>Lábios cerrados, apertados, fazendo biquinho ou tremendo</i>
13	Clenching or grinding teeth, chewing or thrusting tongue out	<i>Dentes cerrados ou rangendo, mordendo ou pondo a língua para fora</i>	<i>Dentes cerrados ou rangendo, mordendo a língua ou empurrando-a para fora</i>	<i>Dentes cerrados ou rangendo, mordendo ou pondo a língua para fora</i>
14	Not moving, less active, quiet	<i>Sem se movimentar, menos ativa, quieta</i>	<i>Sem movimentar-se, menos ativa, quieta</i>	<i>Sem se movimentar, menos ativa, quieta</i>
15	Jumping around, agitated, fidgety	<i>Debatendo-se, agitada, inquieta</i>	<i>Debatendo-se, agitada, inquieta</i>	<i>Debatendo-se, agitada, inquieta</i>
16	Floppy	<i>Flácido</i>	<i>Flácido</i>	<i>Flácido</i>
17	Stiff, spastic, tense, rigid	<i>Teso, espástico, tenso, rígido</i>	<i>Espástico, tenso, rígido</i>	<i>Teso, espástico, tenso, rígido</i>
18	Gesturing to or touching part of the body that hurts	<i>Gesticulando na direção de ou tocando a parte do corpo que dói</i>	<i>Tocando ou gesticulando em direção ao membro que dói</i>	<i>Gesticulando na direção de ou tocando a parte do corpo que dói</i>
19	Protecting, favoring or guarding part of the body that hurts	<i>Protegendo, favorecendo ou defendendo a parte do corpo que dói</i>	<i>Protegendo, favorecendo ou defendendo a parte do corpo que dói</i>	<i>Protegendo, favorecendo ou defendendo a parte do corpo que dói</i>
20	Flinching or moving the body part away, being sensitive to touch	<i>Retraindo ou afastando a parte do corpo, sendo sensível ao toque</i>	<i>Encolhendo ou recolhendo a parte do corpo que se encontra sensível ao toque</i>	<i>Retraindo ou afastando a parte do corpo, sendo sensível ao toque.</i>
21	Moving the body in a specific way to show pain (e.g., head back, arms down, curls up, etc.)	<i>Movendo o corpo de maneira específica para demonstrar dor (p. ex.: cabeça para trás, braços para baixo, em posição fetal, etc.)</i>	<i>Mexendo o corpo de uma maneira específica para demonstrar dor (p. ex., cabeça para trás, braços para baixo, encurvar-se, etc.)</i>	<i>Movendo o corpo de maneira específica para demonstrar dor (p. ex.: cabeça para trás, braços para baixo, em posição fetal, encolhido, etc.)</i>
22	Shivering	<i>Tremor</i>	<i>Tremendo</i>	<i>Tremor</i>
23	Change in color, pallor	<i>Alteração na cor, palidez</i>	<i>Alteração de cor, palidez</i>	<i>Alteração na cor, palidez</i>
24	Sweating, perspiring	<i>Sudorese, transpiração</i>	<i>Suando, transpirando</i>	<i>Sudorese, transpiração</i>
25	Tears	<i>Lágrimas</i>	<i>Lágrimas</i>	<i>Lágrimas</i>
26	Sharp intake of breath, gasping	<i>Inspiração brusca, suspiro</i>	<i>Inspiração forçada, suspirando</i>	<i>Inspiração brusca, suspiro</i>
27	Breath holding	<i>Prendendo a respiração</i>	<i>Apneia, prendendo a respiração</i>	<i>Prendendo a respiração</i>

to fill out the 27 items, without the need to be constantly watching the patient (who should only be in the same room), and it can be used both in hospitals and in similar locations during episodes of acute pain. It showed good consistency and reliability in various validation studies.<sup>11,14–16</sup>

We chose the adaptation process developed by Beaton et al<sup>13</sup> because it is considered consistent and detailed to

better match the terms translated to the target language, in this case, Brazilian Portuguese.

A limitation found in the sample of caregivers was that only 40% of the children they cared for had already undergone postoperative experiences because they came from secondary health care services, which may have caused a bias in the sample. Despite the possibility that

**Table 2** Description of the of the back-translation stage of version T1,2

	T1,2 version	RT1 back-translation	RT2 back-translation	RT1,2 back-translation
1	Moaning, whining, whimpering (fairly soft)	Gemendo, choramingando, soluçando (levemente).	Gemendo, choramingando, soluçando (levemente)	Gemendo, choramingando, soluçando (levemente).
2	Crying (moderately loud)	Chorando (moderadamente alto).	Chorando (moderadamente alto).	Chorando (moderadamente alto).
3	Screaming/yelling (very loud)	Chorando/berrando (muito alto).	Gritando/ Berrando (muito alto).	Chorando/berrando (muito alto).
4	A specific sound or word for pain (e.g., a word, cry or type of laugh)	Um som ou palavra específica para a dor (p. ex., choro ou tipo de risada).	Um som ou palavra específica para dor(p. ex., uma palavra, grito ou tipo de sorriso).	Um som ou palavra específica para a dor (p. ex., choro ou tipo de risada).
5	Not cooperating, cranky, irritable, unhappy	Não cooperativa, mal-humorada, irritadiça, triste.	Não cooperativa, irritadiça, triste.	Não cooperativa, mal-humorada, irritadiça, triste.
6	Less interaction with others, withdrawn	Menos interativa com os outros, retraída.	Menos interativo com outras pessoas, retraído.	Menos interativa com os outros, retraída.
7	Seeking comfort or physical closeness	Buscando conforto ou proximidade física.	Procurando por conforto ou aproximação física.	Buscando conforto ou proximidade física.
8	Being difficult to distract, not able to satisfy or pacify	Difícil de distrair, incapaz de ser satisfeito ou acalmado	Difícil de distrair, incapaz de ser satisfeito ou acalmado.	Difícil de distrair, incapaz de ser satisfeito ou acalmado.
9	A furrowed brow	Testa franzida	Sobrancelha enrugada.	Testa franzida.
10	A change in eyes, including: squinching of eyes, eyes opened wide, eyes frowning	Uma alteração nos olhos, incluindo: olhos estrábicos, olhos arregalados, olhos franzidos	Uma alteração dos olhos, incluindo olhos estrábicos, olhos arregalados, olhos carrancudos.	Uma alteração nos olhos, incluindo: olhos estrábicos, olhos arregalados, olhos franzidos.
11	Turning down of mouth, not smiling	Virando a boca para baixo, sem sorrir	Boca direcionada para baixo, sem sorrir.	Virando a boca para baixo, sem sorrir.
12	Lips puckering up, tight, pouting, or quivering	Lábios cerrados, apertados, fazendo biquinho ou tremendo.	Lábios franzidos, cerrados, amuados ou tremendo.	Lábios cerrados, apertados, fazendo biquinho ou tremendo.
13	Clenching or grinding teeth, chewing or thrusting tongue out	Dentes cerrados ou rangendo, mordendo ou pondo a língua para fora.	Dentes cerrados ou rangendo, mordendo a língua ou empurrando-a para fora.	Dentes cerrados ou rangendo, mordendo ou pondo a língua para fora.
14	Not moving, less active, quiet	Sem se movimentar, menos ativa, quieta.	Sem movimentar-se, menos ativa, quieta.	Sem se movimentar, menos ativa, quieta.
15	Jumping around, agitated, fidgety	Debatendo-se, agitada, inquieta	Debatendo-se, agitada, inquieta.	Debatendo-se, agitada, inquieta.
16	Floppy	Flácido	Flácido.	Flácido.
17	Stiff, spastic, tense, rigid	Teso, espástico, tenso, rígido.	Espástico, tenso, rígido.	Teso, espástico, tenso, rígido.
18	Gesturing to or touching part of the body that hurts	Gesticulando na direção de ou tocando a parte do corpo que dói.	Tocando ou gesticulando em direção ao membro que dói.	Gesticulando na direção de ou tocando a parte do corpo que dói.
19	Protecting, favoring or guarding part of the body that hurts	Protegendo, favorecendo ou defendendo a parte do corpo que dói.	Protegendo, favorecendo ou defendendo a parte do corpo que dói	Protegendo, favorecendo ou defendendo a parte do corpo que dói.
20	Flinching or moving the body part away, being sensitive to touch	Retraindo ou afastando a parte do corpo, sendo sensível ao toque.	Encolhendo ou recolhendo a parte do corpo que encontra-se sensível ao toque.	Retraindo ou afastando a parte do corpo, sendo sensível ao toque.
21	Moving the body in a specific way to show pain (e.g. head back, arms down, curls up, etc.)	Movendo o corpo de maneira específica para demonstrar dor (p. ex.: cabeça para trás, braços para baixo, em posição fetal, etc.)	Mexendo o corpo de uma maneira específica para demonstrar dor (p. ex., cabeça para trás, braços para baixo, encurvar-se, etc.	Movendo o corpo de maneira específica para demonstrar dor (p. ex.: cabeça para trás, braços para baixo, em posição fetal, encolhido, etc.)
22	Shivering	Tremor	Tremendo	Tremor
23	Change in color, pallor	Alteração na cor, palidez	Alteração de cor, palidez.	Alteração na cor, palidez.
24	Sweating, perspiring	Sudorese, transpiração.	Suando, transpirando.	Sudorese, transpiração.
25	Tears	Lágrimas	Lágrimas	Lágrimas.
26	Sharp intake of breath, gasping	Inspiração brusca, suspiro.	Inspiração forçada, suspiro.	Inspiração brusca, suspiro.
27	Breath holding	Prendendo a respiração.	Apneia, prendendo a respiração.	Prendendo a respiração.

this factor is limiting in relation to the caregivers' ability to test the items of the NCCPC-PV, this sample was accepted because the instrument was developed not only for post-operative pain, but also for episodes of acute pain, which we believe that all of the patients have experienced several

times. In addition, the sample tested was not composed of patients, but of caregivers with profound knowledge of the behavior of their assisted children, also regarding acute pain. Thus, it was considered as the main factor (and it was even an inclusion criterion) that caregivers had



**Table 3** Clinical characteristics of the reference children (n = 20)

Characteristics		n	%
Age	3.09 years* 30–41 <sup>#</sup>		
Diagnosis	Cerebral palsy	9	45
	Down syndrome	4	20
	Microcephaly	4	20
	Pigmentar Incontinence (Bloch-Sulzberger)	1	5
	Cornelia Lange Myelomeningocele	1	5
Current treatment	Physiotherapy	20	100
	Speech therapy	20	100
	Occupational therapy	20	100
	Hydrotherapy	1	5
	Equine-Assisted Therapy	1	5
Previous admissions	0.0*		
Previous surgeries	0.0*		
Reasons	Whitout surgery	12	60
	Inguinal hernia	3	15
	Cardiac Surgery	2	5
	Heart disease	1	5
	Cleft lip	1	5
	Gastrostomy	1	5
	Cerebralspinal fluid cyst	1	5
	Cryptorchidism	1	5
	Ventriculoperitoneal shunt (VPS) valve change	1	5
	3th ventricle hiperpressure	1	5
	Hyperpressure		

Notes: \*median; <sup>#</sup>interquartile range (IQR).

**Table 4** Demographic characteristics of the health professionals (n = 20)

Characteristics		n	%
Profession	Orthopedic doctor	3	15
	Pediatrician	3	15
	Clinical pain physician	2	10
	Resident doctor	0	0
	Nurse	3	15
	Nursing technician/assistant	2	10
	Occupational therapist	3	15
	Physiotherapist	4	20
Place where they come in contact with patients with cognitive impairment and inability to communicate	Public hospital	14	70
	Private hospital	2	10
	Public outpatient clinic	7	35
	Private outpatient clinic	5	25
Length of experience with patients with cognitive impairment and inability to communicate	< 1 year	1	5
	1–5 years	3	15
	5–10 years	2	10
	10–20 years	6	30
	> 20 years	8	40
Time since graduation	< 1 year	0	0
	1–5 years	0	0
	5–10 years	0	0
	10–20 years	10	50
	> 20 years	10	50

**Table 5** Demographic characteristics of the caregivers (n = 20)

Characteristics		n	%
Relationship to the patient	Mother	17	85
	Father	1	5
	Aunt	2	10
Daily amount of time spent with the patient	6–12 hours	1	5
	12–18 hours	7	35
	>18 hours	11	55
	Alternate days	1	5
Occupation	Homemaker	15	75
	Doorman	1	5
	Hair stylist	1	5
	Nursing technician	1	5
	Business administrator	1	5
	Dentist	1	5

experience with children with CIIC, even if they had not had postoperative experiences.

Regarding their profile, most of the caregivers were female (95%), mothers of the patients (85%), who spent more than 12 hours a day as caregivers (90%), and who had the home environment as the main setting for their daily activities (75%). All of these factors are related, and they reveal the great impact that ID has on families. This almost exclusive participation of females, especially mothers, as caregivers, followed the same trend as that described in the literature.<sup>17,18</sup>

To quantify the level of experience of our sample of health professionals, we analyzed the length of their experience with their professional activities. We observed that all professionals (100%) had more than 10 years into their professions since graduation. With this objective, we also found that 14 professionals (70%) had more than 10 years of experience treating patients with CIIC. This sample was considered experienced in relation to their health professional activities, contributing to the good quality of the adaptation. The age, although not showing a significant difference, revealed a distance of 10 years between caregivers and health professionals.

The entire sample (n = 40) had almost all of the combined medians between 4 and 5 (only one median was of 3.5), that is, overall, the translated items were considered “clear” and “very clear.”

At the end of the process, the Br-NCCPC-PV, which was adapted and is described in ►Figure 2, was considered appropriate for professionals and reference caregivers to be used for patients with CIIC after validation, and it was well understood.

## Conclusion

The present study adapted the NCCPC-PV to Brazilian Portuguese to enable a better understanding when applied by caregivers and health professionals to measure acute pain in Brazilian children. After the whole process, the Br-NCCPC-PV will be validated in Brazilian patients to assess its internal and external consistency, in order to test its reliability.

**Table 6** Medians and percentiles after the pre-test clarity assessment

	Translation of the prefinal version	Health professionals		Caregivers		Overall	
		Medians	Percentiles	Medians	Percentiles	Medians	Percentiles
1	<i>Gemendo, choramingando, soluçando (levemente)</i>	5	3.25–5.0	4	4.0–4.0	4	4.0–5.0
2	<i>Chorando (moderadamente alto)</i>	5	4.0–5.0	4	4.0–4.75	4	4.0–5.0
3	<i>Chorando/berrando (muito alto)</i>	5	5.0–5.0	4	4.0–5.0	5	4.0–5.0
4	<i>Um som ou palavra específica para a dor (p. ex., choro ou tipo de risada)</i>	4.5	2.25–5.0	4	2.25–4.0	4	2.25–5.0
5	<i>Não cooperativa, mal-humorada, irritada, triste</i>	5	4.0–5.0	4	4.0–4.75	4	4.0–5.0
6	<i>Menos interativa com os outros, retraída</i>	5	4.0–5.0	4	3.25–4.0	4	4.0–5.0
7	<i>Buscando conforto ou proximidade física</i>	5	4.0–5.0	4	3.0–4.0	4	4.0–5.0
8	<i>Difícil de distrair, incapaz de ser satisfeita ou acalmada</i>	5	4.0–5.0	4	3.25–4.0	4	4.0–5.0
9	<i>Testa franzida</i>	5	4.0–5.0	2	2.0–4.0	4	2.0–5.0
10	<i>Uma alteração nos olhos, incluindo: olhos estrábicos, olhos arregalados, olhos franzidos</i>	5	4.0–5.0	3.5	2.0–4.0	4	2.25–5.0
11	<i>Virando a boca para baixo, sem sorrir</i>	4	2.25–5.0	2	1.0–4.0	3.5	2.0–4.75
12	<i>Lábios cerrados, apertados, fazendo biquinho ou tremendo</i>	5	4.0–5.0	3.5	2.0–4.0	4	3.0–5.0
13	<i>Dentes cerrados ou rangendo, mordendo ou pondo a língua para fora</i>	4.5	3.25–5.0	4	2.0–4.0	4	2.25–5.0
14	<i>Sem se movimentar, menos ativa, quieta</i>	5	3.5–5.0	4	4.0–4.75	4	4.0–5.0
15	<i>Debatendo-se, agitada, inquieta</i>	5	5.0–5.0	4	4.0–5.0	5	4.0–5.0
16	<i>Flácido</i>	5	3.25–5.0	2	1.25–4.0	4	2.0–5.0
17	<i>Teso, espástico, tenso, rígido</i>	5	5.0–5.0	4	2.0–4.0	4	3.25–5.0
18	<i>Gesticulando na direção ou tocando a parte do corpo que dói</i>	5	5.0–5.0	4	2.0–4.0	4	4.0–5.0
19	<i>Protegendo, favorecendo ou defendendo a parte do corpo que dói</i>	5	4.0–5.0	4	2.0–4.0	4	3.25–5.0
20	<i>Retraindo ou afastando a parte do corpo, sendo sensível ao toque</i>	5	4.25–5.0	4	3.0–4.0	4	4.0–5.0
21	<i>Movendo o corpo de maneira específica para demonstrar dor (p. ex.: cabeça para trás, braços para baixo, em posição fetal, corpo encolhido, etc.)</i>	5	4.0–5.0	4	4.0–4.0	4	4.0–5.0
22	<i>Tremor</i>	5	4.0–5.0	4	3.25–5.0	4.5	4.0–5.0
23	<i>Alteração na cor da pele, palidez</i>	5	4.0–5.0	4	3.0–5.0	4	3.25–5.0
24	<i>Sudorese, transpiração</i>	5	4.0–5.0	2	1.0–4.0	4	2.0–5.0
25	<i>Lágrimas</i>	5	4.0–5.0	5	4.0–5.0	5	4.0–5.0
26	<i>Inspiração brusca, suspiro</i>	5	3.25–5.0	4	2.0–4.0	4	3.0–5.0
27	<i>Prendendo a respiração</i>	5	3.0–5.0	4	2.0–4.0	4	3.0–5.0

**Table 7** Comparison between caregivers and health professionals regarding age, gender and schooling

Characteristics		Caregivers		Health professionals		p-value
		n	%	n	%	
Age (in years)		33.5*		43.5*		1.0 <sup>△</sup>
		30–41 <sup>#</sup>		40–52 <sup>#</sup>		
Sex <sup>‡</sup>	Female	19	95	18	90	1.0
	Male	1	5	2	10	
Schooling <sup>Ω</sup>	Higher education	2	10	20	100	0.001
	High-school graduate	6	30	0	0	
	Elementary-school graduate	9	45	0	0	
	Incomplete elementary school	3	15	0	0	

Notes: \*median; <sup>#</sup>interquartile range (IQR); <sup>‡</sup>Fisher exact test; <sup>Ω</sup>Chi-squared test; <sup>△</sup>Mann-Whitney test.



### Lista de Verificação de Dor em Crianças Não Comunicantes – Versão Pós-Operatória (Br-NCCPC-PV)

Nome: \_\_\_\_\_ Unid. / Prontuário Nº: \_\_\_\_\_ Data: \_\_\_\_\_ (dd/mm/aa)  
 Observador: \_\_\_\_\_ Horário Inicial: \_\_\_\_\_ Horário Final: \_\_\_\_\_

Com que frequência essa criança tem mostrado estas reações nos últimos 10 minutos? Por favor, circule um número para cada reação. Caso um item não se aplique a essa criança (por exemplo, se a criança não consegue estender as mãos), então indique “não aplicável” para tal item.

**0 = NUNCA/SEM REAÇÃO 1 = UM POUCO 2 = COM CERTA FREQUÊNCIA 3 = COM MUITA FREQUÊNCIA NA = NÃO APLICÁVEL**

**I. Vocal**

1.	Gemendo, reclamando, choramingando (levemente).....	0	1	2	3	NA
2.	Chorando (moderadamente alto) .....	0	1	2	3	NA
3.	Gritando/berrando (muito alto) .....	0	1	2	3	NA
4.	Um som ou palavra específica para a dor (p. ex., choro ou tipo de risada) .....	0	1	2	3	NA

**II. Social**

5.	Não cooperativa, mal-humorada, irritada, triste.....	0	1	2	3	NA
6.	Menos interativa com os outros, retraída .....	0	1	2	3	NA
7.	Buscando conforto ou proximidade física .....	0	1	2	3	NA
8.	Difícil de distrair, incapaz de ser satisfeito ou acalmado .....	0	1	2	3	NA

**III. Facial**

9.	Testa franzida, com o rosto tenso.....	0	1	2	3	NA
10.	Uma alteração nos olhos incluindo olhos apertados, olhos arregalados ou olhos franzidos.....	0	1	2	3	NA
11.	Virando a boca para baixo, sem sorrir, fazendo beicinho.....	0	1	2	3	NA
12.	Lábios cerrados, apertados, fazendo biquinho ou tremendo. ....	0	1	2	3	NA
13.	Dentes cerrados ou rangendo, mastigando ou pondo a língua para fora .....	0	1	2	3	NA

**IV. Atividade**

14.	Sem se movimentar, menos ativa, quieta.....	0	1	2	3	NA
15.	Debatendo-se, agitada, inquieta .....	0	1	2	3	NA

**V. Corpo e Membros**

16.	Flácido, com o corpo relaxado .....	0	1	2	3	NA
17.	Teso, espástico, tenso, rígido .....	0	1	2	3	NA
18.	Gesticulando na direção ou tocando a parte do corpo que dói .....	0	1	2	3	NA
19.	Protegendo, favorecendo ou defendendo a parte do corpo que dói .....	0	1	2	3	NA
20.	Encolhendo ou recolhendo a parte do corpo que encontra-se sensível ao toque .....	0	1	2	3	NA
21.	Movendo o corpo de maneira específica para demonstrar dor (p. ex.: cabeça para trás, braços para baixo, em posição fetal, corpo encolhido, etc.) .....	0	1	2	3	NA

**VI. Fisiológico**

22.	Tremor .....	0	1	2	3	NA
23.	Alteração na cor da pele, palidez .....	0	1	2	3	NA
24.	Sudorese, suando muito, transpirando.....	0	1	2	3	NA
25.	Lágrimas .....	0	1	2	3	NA
26.	Inspiração brusca, ofegante .....	0	1	2	3	NA
27.	Prendendo a respiração .....	0	1	2	3	NA

#### RESUMO DA PONTUAÇÃO:

Categoria	I	II	III	IV	V	VI	TOTAL
Pontuação:							

Versão 01.2004 © 2004 Lynn Breau, Patrick McGrath, Allen Finley, Carol Camfield

**Fig. 2** Brazilian portuguese version of Non-communicating Children's Pain Checklist -Postoperative Version (Br-NCCPC-PV).

### USANDO O Br-NCCPC-PV

A NCCPC-PV foi criada para ser usada em crianças com idade de 3 a 18 anos que sejam incapazes de falar por causa de dificuldades ou deficiências cognitivas (mentais/intelectuais). Pode ser usada em crianças com ou sem incapacidades ou deficiências físicas. As descrições dos tipos de crianças usadas para validar a NCCPC-PV podem ser encontradas em: Breau, L.M., Finley, G.A., McGrath, P.J. & Camfield, C.S. (2002). Validation of the Non-Communicating Children's Pain Checklist - Postoperative Version. *Anesthesiology*, 96 (3), 528-535. A NCCPC-PV foi criada para ser usada sem treinamento por pais e cuidadores, ou por outros adultos que não tenham familiaridade com uma criança específica (não a conheçam bem).

A NCCPC-PV pode ser livremente copiada para uso clínico ou em pesquisas financiadas por entidades sem fins lucrativos. Entidades com fins lucrativos devem entrar em contato com Lynn Breau: [Pediatric Pain Research, IWK Health Centre, 5850 University Avenue, Halifax, Nova Scotia Canada, B3J 3G9 \(lbreau@ns.sympatico.ca\)](mailto:PediatricPainResearch@iwhk.com).

A NCCPC-PV foi criada com a intenção de ser usada para dor após uma cirurgia ou devido a outros procedimentos conduzidos em uma unidade hospitalar que provoquem dor. Em caso de suspeita de dor de curta ou longa duração em crianças em domicílio ou em condições de cuidados domiciliares a longo prazo, a **Lista de Verificação de Dor em Crianças NÃO COMUNICANTES – Revisada (NCCPC-R)** pode ser usada. Pode ser obtida entrando-se em contato com Lynn Breau. Informações sobre o NCCPC-R podem ser encontradas em: Breau, L.M., McGrath, P.J., Camfield, C.S. & Finley, G.A. (2002). Psychometric Properties of the Non-communicating Children's Pain Checklist-Revised. *Pain*, 99, 349-357.

#### APLICAÇÃO:

Para preencher a NCCPC-R, baseie suas observações no comportamento da criança durante **10 minutos**. *Não é necessário vigiar a criança continuamente durante esse período*. Contudo, recomenda-se que o observador esteja na presença da criança durante a maior parte do tempo (p. ex.: esteja no mesmo cômodo que a criança). Embora períodos de observação mais curtos possam ser usados, as pontuações de corte descritas abaixo podem não ser aplicáveis.

Ao final do tempo de observação, indique com que frequência cada item foi visto ou ouvido. Isso não deve se basear no comportamento típico da criança ou em relação ao que ele(a) geralmente faz. Um guia para se decidir a frequência dos itens encontra-se abaixo:

0	=	Não apresentado de forma alguma durante o período de observação. (importante, se o item não foi observado porque a criança não foi capaz de executá-lo, deve-se marcá-lo como "NA").
1	=	Visto ou ouvido raramente (quase nunca), porém presente.
2	=	Visto ou ouvido algumas vezes, mas não de forma contínua (não o tempo todo).
3	=	Visto ou ouvido com frequência, quase continuamente (quase o tempo todo); qualquer um perceberia isso facilmente caso visse a criança por poucos instantes durante este período de observação
NA	=	Não aplicável. Esta criança não é capaz de executar essa ação.

#### PONTUAÇÃO:

1. Some as pontuações para cada sub-escala e insira abaixo o número dessa sub-escala no Resumo da Pontuação ao final da tabela. Itens marcados "NA" recebem pontuação "0" (zero).
2. Some todas as pontuações das sub-escalas para obter a Pontuação Total.
3. Verifique se a pontuação da criança é maior do que a pontuação de corte.

#### NOTA DE CORTE:

Com base nas pontuações de 24 crianças com idades de 3 a 18 anos (Breau, Finley, McGrath & Camfield, 2002), uma **Pontuação Total de 11 ou mais** indica que a criança tem **dor moderada a severa**. Com base em dados não publicados dessa mesma amostra, uma **Pontuação total de 6-10** indica que a criança tem **dor leve**. Quando os pais e cuidadores preencheram a NCCPC-PV no hospital para o grupo de estudos, o mesmo mostrou-se preciso em 88% dos casos. Quando outros observadores preencheram a NCCPC-PV, o mesmo foi preciso em 75% dos casos. Uma pontuação total de 10 ou menos indica menos que uma dor moderada/severa. Isso estava correto no grupo de estudo para pais e cuidadores em 81% das vezes, e para outros observadores em 63% das vezes.

#### USO DAS NOTAS DE CORTE:

Como ocorre com toda ferramenta de observação, deve-se ter cuidado ao usar as pontuações de corte, pois elas podem não ser 100% precisas. Elas não devem ser usadas como a única base para se decidir se uma criança deve receber tratamento para dor. Em alguns casos, as crianças podem ter pontuações mais baixas quando há dor. Para instruções de uso mais detalhadas do NCCPC-PV em tais situações, por favor, consulte o manual completo, disponibilizado por Lynn Breau:

Fig. 2 (Continued)

**Conflict of Interests**

The authors have no conflict of interests to declare.

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