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Brazilian Portuguese version of the Patient Competency Rating Scale (PCRS-R-BR): semantic adaptation and validity

Versão em português brasileiro da Patient Competency Rating Scale (PCRS-R-BR): adaptação semântica e validade

Nicolle Zimmermann,¹ Ana Paula Almeida de Pereira,² Rochele Paz Fonseca¹

Abstract

This study describes the adaptation of a revised Brazilian version of the Patient Competency Rating Scale (PCRS-R-BR), which focuses on executive, mnemonic, and attention functions. Evidence of content-based and external validity is also reported. The cross-cultural adaptation was conducted in five phases: 1) translations and back translations; 2) item analysis by authors; 3) classification by experts; 4) revisions and reformulations by authors; 5) pilot study with a sample of patients with mild and moderate/severe traumatic brain injury (TBI). Data were analyzed descriptively, and the PCRS-R-BR scores of groups with mild vs. moderate/severe TBI were compared using the Mann-Whitney test. Patients and their relatives were divided into groups and compared using repeated-measures analysis. The results of the PCRS-R-BR questionnaire for relatives and discrepancy scores of patients with moderate/severe TBI revealed significantly more impairment than that found in the group of patients with mild TBI. There were significant differences between item and total scores of both groups of patients and relatives. Results indicated a high level of item content agreement between experts. This study found initial evidence of PCRS-R-BR content-based and external validity when the questionnaire was applied to patients with mild and moderate/severe TBI and their relatives.

Keywords: Patient Competency Rating Scale, scales, validation studies, brain injuries.

Resumo

O presente artigo teve como objetivo apresentar a adaptação transcultural e evidências de validade externa e de conteúdo da versão brasileira revisada da Patient Competency Rating Scale (PCRS-R-BR), com foco nas funções executivas, mnemônicas e atencionais. A adaptação transcultural incluiu cinco fases: 1) tradução e retrotradução; 2) análise de itens por autores; 3) análise de especialistas; 4) revisões e reformulações dos autores; 5) estudo piloto em pacientes com traumatismo cranioencefálico (TCE) leve e moderado/grave. Os dados foram analisados descritivamente e os pacientes com TCE leve e moderado/grave foram comparados nos escores da PCRS-R-BR pelo teste Mann-Whitney. Os pacientes e familiares foram comparados por grupo através da análise de medidas repetidas. Os pacientes com TCE moderado/grave tiveram maior prejuízo que os pacientes com TCE leve no formulário da PCRS-R-BR dos familiares e no escore de discrepância entre pacientes e familiares. Os resultados indicam bons e altos níveis de concordância entre especialistas frente aos componentes avaliados pelos itens. Esse estudo apresentou evidências iniciais de validade de conteúdo da PCRS-R-BR para pacientes com TCE leve e moderado/severo e seus familiares.

Descritores: Patient Competency Rating Scale, escalas, estudos de validade, lesões cerebrais.

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Introduction

The main goal of neuropsychological assessment is to identify the cognitive and behavioral strengths and weaknesses of individuals and to characterize their neurocognitive functioning profile of dissociations and associations.^{1,2} Classical performance measurement methods are the most frequently used in clinical and research settings. However, the applicability of neuropsychological assessments has moved beyond populations with acquired brain injuries, which has raised concerns about the ecological validity of assessment data.^{3,4} Scales and questionnaires that investigate cognition improve the ecological and functional validity of test performance data.⁵ Moreover, these tools may also contribute to the investigation of anosognosia, a clinical condition defined by impaired self-awareness.⁶

Anosognosia has been diagnosed in different clinical populations, such as patients with traumatic brain injury (TBI), Alzheimer's disease, schizophrenia, and Huntington's disease. The presence of anosognosia has important implications for interventions in neuropsychology.⁷ During assessment, the evaluation of impaired self-awareness is especially relevant because of its impact on complaint self-report, which may also affect the decision to seek neuropsychological care. In some cases, adherence to rehabilitation may be affected due to lack of patient self-awareness, which may change the outcome after rehabilitation as well.^{8,9} For those reasons, the investigation of this metacognitive function is relevant for clinical and research purposes.

Deaton,¹⁰ defined three methods of self-awareness assessment: 1) discrepancy between patient's and relative's self-reported scores; 2) discrepancy between patient's and clinician's self-reported scores; 3) discrepancy between patient's self-report and his/her performance on cognitive tasks. A number of instruments have been developed to assess self-awareness, such as questionnaires, scales, and interviews. The Self-Awareness of Deficits Interview (SADI)¹¹ investigates quantitative and qualitative aspects of self-awareness, such as functional implications of deficits and the ability to set realistic goals. A study found that SADI had a better correlation with executive function (EF) tests than the Dysexecutive Questionnaire, for example, and demonstrated that it was a predictor of severity in a sample of patients with TBI.¹² The Awareness Questionnaire (AQ),¹³ another similar instrument, assesses how well patients perform some activities when compared with their pre-injury performance. After 1 year, AQ score was predicted by the time taken to follow commands in a group of people with acute TBI.¹⁴ The same study also used the Patient Competency Rating Scale (PCRS)¹⁵

and found similar results, but PCRS scores seemed to improve over time, whereas AQ scores did not, which may indicate that different things are measured by these two instruments.

The PCRS is one of the most frequently used instruments worldwide to assess self-awareness impairment in patients with TBI.¹⁶ The original version comprises 30 items that assess emotion, activities of daily living (ADL), cognition and interpersonal relationships. In addition, the PCRS has been adapted for use in rehabilitation centers (PCRS-NR),¹⁷ and its validity for use with stroke patients has been demonstrated.¹⁸ In addition, the PCRS has been adapted and validated for use in different cultures.^{19,20} Some studies have found a correlation with measures of EFs in samples of patients with TBI²¹ and with specific (medial and right dorsal) regions of the prefrontal cortex.²² Such data are indicative of what underlies self-awareness assessed by the PCRS.

Despite the relevance of self-awareness assessment, no tools are available for that in Brazil. A Brazilian study has used the Questionário de Demência (Dementia Questionnaire)²³ to measure cognitive self-awareness in patients with Alzheimer's disease. However, there are no appropriate adaptations and validity publications as far as we know, and no studies about self-awareness measures for neurological samples in Brazil have been published. Given the well-known cultural and linguistic bias involved in using non-adapted instruments,²⁴ the demand in this area has not been met. Valentini et al.²⁵ adapted the Harter self-perception profile for children, which assesses competencies in different aspects of life. However, as far as we know, no scales to assess the self-awareness of patients with neurological diseases have been adapted for use in Brazil. In addition, Brazilian centers of neuropsychology are under great pressure due to the high number of patients and lack of time, which is further complicated by the time necessary to apply assessment tools. Those two reasons led us to develop a project to adapt a self-awareness questionnaire transculturally and semantically and produce a tool that does not take long to apply and that has high clinical relevance and applicability. Our review of the literature and our clinical experience identified the three main cognitive demands of patients with TBI: EFs,²⁶ memory,²⁷ and attention.²⁸

Therefore, our study describes the transcultural adaptation and the analysis of content-based validity of the PCRS for patients with EF, memory, and attention deficits. In addition, evidence is reported of the external validity of the PCRS-R-BR in a sample of patients with TBI and their relatives.

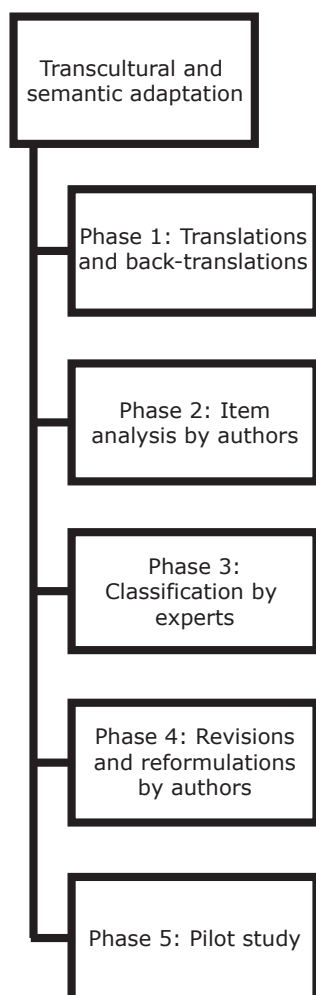


Figure 1 - Flowchart of adaptation phases

Method

The adaptation of the PCRS and the analysis of its content-based validity was conducted in five phases, shown in Figure 1. Agreement rates for content validity and classification by experts were based on the method described by Andrés & Marzo.²⁹ The original author of the PCRS was contacted and authorized adaptation.

Participants

This study included 75 adults. Table 1 shows the characteristics of participants in each study phase. The clinical sample in the pilot study is described in detail below.

Description of pilot sample

The pilot sample comprised 62 adults (age range: 18 to 72 years) with mild (41.9%) or moderate/severe (58.1%) TBI. Participants were recruited by convenience sampling

using contacts collected from medical records of hospitals in Porto Alegre, Brazil. This study was approved by the Ethics Committee of Pontifícia Universidade Católica do Rio Grande do Sul (PUCRS), Brazil (no. 10/05134).

Severity of trauma was classified according to the Glasgow Coma Scale (GCS) score at hospital admission, self-report of loss of consciousness (< 30 minutes = mild; 30 minutes to 1 day = moderate; > 1 day = severe) or posttraumatic amnesia (< 24 hours = mild; 1-7 days = moderate; > 7 days = severe).³⁰ Some patients presented with psychiatric symptoms (56.4%), defined according to self-report or the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I).^{31,32} However, patients with mild or moderate/severe TBI did not differ in presence of psychiatric symptoms ($p = 0.568$). Sociodemographic and clinical data are shown in Table 1.

Procedures and instruments

The method used in this study was based on the procedure described by Fonseca et al.³³ for the adaptation of verbal neuropsychological tests. Neuropsycholinguistic and psychometric factors were analyzed in three steps: translation, analysis by experts and pilot study. These steps evaluate the equivalence of cross-cultural adaptations, as suggested by Reichenheim et al.,³⁴ as well as the translation and back-translation processes detailed in Gjersing et al.³⁵

Translations and back-translations

The questions were translated independently by two independent translators, generating two translated versions. After that, the two translations were back-translated by other translators, also working independently. These two back-translated versions were analyzed and compared with the original version. The purpose of these two steps was to ensure the semantic equivalence of items and to define the best form to express their meaning.

Item analysis by authors

The initial purpose of this adaptation of the PCRS was to include only EF, memory, and attention items. Therefore, the cognitive constructs of the 30 original PCRS items were analyzed and classified by double-blinded experts. The agreement index was calculated according to what was expected for each item and using the expert experiences of one of the authors as the criterion standard.

Complementary changes and inclusions were made during this phase. The version of the PCRS-R-BR to be used with relatives had the same scale questions using the third person. The original PCRS can be accessed in <http://www.tbims.org/combi/pcrs/index.html>.

Table 1 - Description of participants in each phase

Phase	Participants	Characterization
(1) Translations and back-translations	Step 1 - translation: n = 2 interpreters	Step 1 - translation interpreters: - PhD, neuropsychology professor - Master's candidate in neuropsychology
	Step 2 - back-translation: n = 2 interpreters	Step 2 - back-translation interpreters: Both bilinguals with long-term life experience in English-speaking countries - PhD, neuropsycholinguistics professor - PhD candidate in neuropsychology
(2) Item analysis by authors	n = 3 neuropsychologists	- 2 PhD, neuropsychology professors - Master's candidate in neuropsychology
(3) Analysis by experts	n = 8 experts	Graduated neuropsychology experts (n = 6) Undergraduate psychology experts (n = 2)
(4) Revisions and reformulations by authors	n = 3 neuropsychologists	- 2 PhD, neuropsychology professors - Master's candidate in neuropsychology
(5) Pilot study	n = 62 patients with TBI	Mild (41.9%); moderate/severe (58.1%)

Variables	Mild		Moderate/severe		p*
	Mean	SD	Mean	SD	
Age (years)	38.38	13.42	35.39	14.88	0.321
Education (years)	9.54	4.06	9.11	3.44	0.477
Socioeconomic status [†]	23.12	6.29	21.22	5.54	0.184
Frequency of reading and writing habits	10.58	5.74	8.83	5.86	0.179
Time post-onset (months)	17.30	17.43	25.58	25.54	0.134
MMSE score	26.23	3.08	24.47	3.40	0.045

MMSE = Mini Mental State Examination; SD = standard deviation; TBI = traumatic brain injury.

The authors are the same in all study phases.

* $p \leq 0.05$.[†] Associação Brasileira de Empresas de Pesquisa (2008). <http://www.abep.org/novo/Content.aspx?ContentID=301>**Classification by experts**

During this phase, cognitive constructs were evaluated, and the items were classified to confirm that they were clearly understood. Each expert made these classifications independently.

Revisions and reformulations by authors

The authors analyzed the suggestions made by the group for the final changes of different items for the pilot study. Suggestions were read, discussed and voted by the three authors.

Pilot study

The PCRS-R-BR was applied individually to patients with TBI. The items were read aloud by the examiner, and a printed form was handed out for the participants to read if necessary. No additional explanations were given to participants about the meaning of the questions to avoid differences in item interpretation. However, questions were read as many times as necessary for participants to process and understand them. Participants with clinical

signs of poor language comprehension and use were not included in the study. Also, based on our clinical experience with neurological patients, we decided to use the PCRS-R-BR as a part of a clinical interview and not as a self-administered scale. Clinical conditions, such as difficulties in visual sensorial processing, low educational level, low processing speed, and visual attention impairments (unintentionally skipped questions), were recorded.

The Mann-Whitney test for non-parametric data was used to analyze whether the PCRS-R-BR differentiates self-awareness between patients with mild and moderate/severe TBI. The level of significance was set at $p \leq 0.05$. Total scores of the versions applied to patients and their relatives, as well as discrepancy scores (patients' total score minus relatives' total score) were compared between the groups of patients with TBI. Moreover, repeated-measures analysis was used to compare scores within patient groups and the scores of relatives in each group of patients with TBI to evaluate whether the scores of patients and relatives were discrepant.

Table 2 - Translations and back-translations

Original question	Translation 2	Translation 1	Back-translation 1	Back-translation 2	Final version
How much of a problem do I have in remembering names of people I see often?	Quanta dificuldade tenho em lembrar nomes de pessoas que encontro frequentemente?	Quanta dificuldade eu tenho em lembrar o nome das pessoas que eu vejo frequentemente?	How hard is it for me to remember the name of people who I frequently see?	How much difficulty do I have in remembering the names of people I see often?	Quanta dificuldade você tem em se lembrar do nome das pessoas que você vê frequentemente?
How much of a problem do I have in remembering my daily schedule?	Quanta dificuldade tenho em lembrar meus compromissos do dia?	Quanta dificuldade eu tenho em me lembrar dos meus horários e compromissos do dia?	How hard is it for me to remember my schedules and appointments of the day?	How much difficulty do I have to remember my schedule and appointments for the day?	Quanta dificuldade você tem em se lembrar dos seus horários e compromissos do dia?
How much of a problem do I have in recognizing when something I say or do has upset someone else?	Quanta dificuldade tenho em perceber que algo que disse ou fiz chateou outra pessoa?	Quanta dificuldade eu tenho em reconhecer quando alguma coisa que eu digo ou faço deixa alguém chateado?	How hard is it for me to notice that something I say or do annoys someone?	How much difficulty I have in recognizing when something I say or do makes someone upset?	Quanta dificuldade você tem em perceber que algo que disse ou fez chateou outra pessoa?

Results

Translations and back-translations

Table 2 shows examples of translated and back-translated items. Most items did not have any notable differences; however, some terms were different, as in the case of “recognizing” and “notice” on back-translation. At this point, the translated versions were analyzed, and the authors chose the better Brazilian Portuguese word (semantically and culturally) while reading it in English language context. Note that in the column “final version”, the authors decided to rewrite the questions using the second person, instead of the first person, during the phase of Item analysis by authors, as described in the methods section.

Item analysis by authors

The selection of EF items and memory constructs by the authors is shown in Table 3. Final cognitive construct consensus was reached according to the contribution made by the third expert.

Table 4 shows that about 53% of the items had 75% or greater agreement among the experts in the classification of cognitive constructs. Sixteen were included; the following items of the original version were excluded: 2, 3, 4, 5, 13, 14, 18, 19, 21, 22, 27, 28, 29, and 30. Question 13 assessed memory, but it was excluded because the structure and content were unspecific. Question 14 was also excluded because it asked about driving. Although driving requires many EFs, experts agree that most patients with brain injury are advised not to drive for medical reasons, and, therefore, this question might not be applicable to most patients.

As suggested by the first classification made by

experts, EF, memory and attention were the cognitive constructs analyzed by the group of experts. Table 3 shows the expert classification of cognitive constructs for each item made.

Revisions and reformulations made by the authors

After analyzing the suggestions made by the experts, the authors either approved changes or not. They decided to include one more question for focused attention only. Additionally, an extra option, “not applicable” (translated to Brazilian Portuguese as *não se aplica*), was included for activities or responsibilities that patients do not have. The answers were scored 1 to 5, and both the options “can do with ease” and “not applicable” were scored 5. Table 4 shows the changes suggested by the neuropsychology experts for the first version of items. Appendices 1 and 2 show the final versions of the PCRS-R-BR for patients and relatives.

Pilot study

Results revealed that there were no significant differences between the groups of patients with mild (mean [M] = 65.31; standard deviation [SD] = 9.51) and moderate/severe (M = 66.36; SD = 11.45) TBI ($p = 0.553$). However, the total score for relatives was significantly different ($p = 0.007$), and the group with mild TBI (M = 71.31; SD = 14.58) had higher scores than the group with moderate/severe TBI (M = 59.81; SD = 19.06). Finally, the discrepancy score was also different between groups ($p = 0.020$) (mild TBI M = -5.54; SD = 14.73; moderate/severe M = 5.47; SD = 20.36). The results of the comparison of PCRS-R-BR item and total scores within the groups of patients and their relatives

Table 3 - Cognitive constructs of the original Patient Competency Rating Scale as classified by experts

Items/experts	Specialist 1	Specialist 2	Specialist 3	Agreement rate (%)
1	EF	ADL	EF	66.6
2	ADL	ADL	ADL	100
3	ADL	ADL, EF	ADL	100
4	ADL	ADL	ADL	100
5	ADL	ADL	ADL	100
6	EF	EF	EF	100
7	EF	EF, MEM	EF	100
8	EF	EF	EF	100
9	EF	EF	EF	100
10	EP-MEM	EP-MEM	EP-MEM	100
11	SEM-MEM	SEM-MEM	SEM-MEM	100
12	PROSP-MEM	PROSP-MEM	PROSP-MEM	100
13	MEM	MEM	MEM	100
14	ADL	EF, praxis	EF, praxis	66.6
15	EF	EF	EF	100
16	EF	EF	EF	100
17	EF	EF	EF	100
18	Emotions	Emotions	Emotions	100
19	Emotions	Emotions	Emotions	100
20	EF	EF	EF	100
21	Emotions	Emotions	Emotions	100
22	EF	Emotions	Emotions	100
23	EF, TOM	EF, TOM	EF, TOM	100
24	EF	EF	EF	100
25	EF	Language comprehension	EF	66.6
26	EF	EF, PROSP-MEM	EF	100
27	Emotions	Emotions	Emotions	100
28	Emotions	Emotions	Emotions	100
29	Emotions	Emotions	Emotions	100
30	Emotions	Emotions	Emotions	100

ADL = activity of daily living; EF = executive functions; EP = episodic; MEM = memory; PROSP = prospective; SEM = semantic; TOM = theory of mind.

are shown in Table 5. There were significant differences within groups, and the group with moderate/severe TBI had differences in more items than the group with mild TBI, but the differences were not statistically significant.

Discussion

This study described the process of PCRS adaptation to Brazilian reality, culture and language. Moreover, it

used descriptive and statistical analysis to evaluate the instrument's content-based and external validity. The PCRS-R-BR adaptation and validation process could not be directly compared with previous published versions of the PCRS because the scale's content and number of items have been changed. Therefore, our findings will be discussed in terms of general expectations in each phase of the process, as well as of expectations for a self-awareness assessment instrument.

Table 4 - Classification of cognitive components by experts

Question	Cognitive components	%
1	Planning	75
2	Planning	62.5
3	Planning	87.5
4	Initiation	100
5	Focused attention	62.5
6	Episodic memory	75
7	Episodic-semantic memory	87.5
8	Prospective memory	62.5
9	Flexibility	50
10	Flexibility	100
11	Flexibility	37.2
12	Inhibition	62.5
13	Self-monitoring	50
14	Planning	75
15	Flexibility	50
16	Planning	62.5
17	Sustained attention	100
Examples of item changes according to suggestions made by experts		
Initial version	Final version	
Quanta dificuldade eu tenho em pedir ajuda quando estou confuso(a)?	Quanta dificuldade você tem em pedir ajuda quando está confuso(a) para resolver um problema ou quando não entende alguma coisa?	
Quanta dificuldade eu tenho em agir de modo esperado quando estou entre amigos?	Quanta dificuldade você tem em agir de modo esperado quando está entre amigos? Por exemplo, cuidando para não fazer coisas que as pessoas não gostam.	
Quanta dificuldade eu tenho em manter-me envolvido nas atividades de trabalho mesmo quando estou me sentindo entediado(a) ou cansado(a)?	Quanta dificuldade você tem em se manter envolvido em atividades obrigatórias que tem que terminar mesmo quando está se sentindo cansado ou entediado?	

Translations and back-translations

The translations and back-translations raised especially important issues regarding the main structure of sentences and questions, because some structures used in English, such as “how much of a problem,” do not exist in Brazilian Portuguese and cannot be literally translated. Moreover, some divergent expressions were used, and some had similar meanings, which was discussed and clarified during the phase of analysis by experts.

Item classification by experts

This phase was important for the selection of the main items of EF, memory and attention, one of the main purposes of this adaptation. Results revealed a high level of agreement between experts. The items for which there was no agreement between experts were the ones in which the activity or ability demanded many functions, or at least two equally important functions, such as in item 11 of the PCRS-R-BR. This phenomenon was expected because different cognitive functions are related, and

in the real world functions are not used separately by individuals, particularly not in the case of EF.

In addition, in this phase the questions were rewritten in the second person, instead of in the first person, to address the difficulties that the patients had in attention, language comprehension, and processing speed. Similar impairments have been described in other studies about TBI. To our knowledge, this is the first scale in which the questionnaire was adapted to obtain more accurate results from patients with TBI. Moreover, the authors included an item (number 17) that assesses sustained attention, because the original PCRS items did not have questions about attention alone. The authors also included the “not applicable” option. This inclusion was essential because some patients did not do some activities, or had never experienced some situations.

Classification by experts and revisions and reformulations by authors

The content-based analysis used to validate the PCRS-R-BR revealed high rates of agreement between

Table 5 - Comparative analysis of item and total scores within groups of patients and their significant others

Items	Mild						Moderate/severe					
	Patient		Significant other		F	p	Patient		Significant other		F	p
	M	SD	M	SD			M	SD	M	SD		
1	4.54	0.99	4.62	0.80	0.15	0.703	4.33	0.96	3.75	1.42	5.31	0.027*
2	3.38	1.20	4.04	1.22	4.97	0.035*	3.78	1.15	3.14	1.44	4.01	0.053*
3	3.92	1.06	4.19	1.17	1.20	0.283	4.39	0.96	3.78	1.42	6.31	0.017*
4	3.73	1.34	4.35	1.13	4.23	0.050*	3.69	1.31	3.81	1.14	0.21	0.648
5	3.42	1.06	4.08	1.35	3.24	0.084	3.50	1.28	3.42	1.59	0.08	0.782
6	3.73	1.00	4.23	1.18	4.22	0.051*	3.67	1.22	3.22	1.48	2.52	0.122
7	4.46	0.76	4.62	0.64	0.61	0.444	3.86	1.22	4.22	0.99	4.08	0.051*
8	3.88	1.14	4.08	1.41	0.35	0.558	3.75	1.50	3.58	1.36	0.29	0.594
9	3.38	1.33	3.96	1.34	3.17	0.087	3.97	1.18	3.83	1.28	0.30	0.586
10	3.54	1.21	3.58	1.30	0.02	0.903	3.53	1.34	3.47	1.28	0.03	0.859
11	3.73	1.15	4.46	0.90	6.30	0.019*	4.11	1.09	3.89	1.12	0.91	0.346
12	4.42	0.90	4.62	0.75	0.63	0.434	4.25	1.00	4.28	1.09	0.01	0.905
13	4.08	1.06	3.92	1.23	0.22	0.642	4.11	1.14	3.44	1.58	4.00	0.053*
14	4.12	1.07	4.00	1.41	0.17	0.683	4.08	1.05	3.69	1.37	1.66	0.206
15	3.69	1.09	4.15	1.08	2.29	0.143	4.14	1.05	3.86	1.05	1.70	0.201
16	4.08	0.98	4.15	1.29	0.14	0.713	4.25	1.08	3.92	1.08	2.12	0.154
17	3.69	1.32	4.27	1.15	3.59	0.070	3.58	1.32	3.83	1.18	0.93	0.342
Total	65.31	9.51	71.31	14.58	5.71	0.025*	66.36	11.45	59.81	19.06	4.57	0.040*

M = mean; SD = standard deviation.

* $p \leq 0.05$.

experts in the classification of general EF, memory and attention functions. Some items that assess EF had lower agreement rates, probably because of the lack of consensus about EF theoretical constructs.³⁶ The contributions made by experts to improve item comprehension were essential for the later understanding of the items by the patients. The content validity found in this study cannot be compared with those reported in previous studies of PCRS because they analyzed the full scale, which is composed of items about activities of daily living, interpersonal relationship, emotion and cognition.¹⁹ In addition, our items were taken from the four factors, and we found no other studies that have investigated specific processes involved in the activities described in the different items.

Pilot study

Our pilot study found data that are partially in agreement with some previous studies about the self-awareness of patients with TBI. Patients with moderate/severe TBI had higher total scores than their relatives, demonstrating that they are less aware of their cognitive abilities than those close to them.³⁷ Surprisingly, relatives of patients with mild TBI overestimated the patients' cognitive abilities, as indicated by their total scores. A

previous study reported similar results for PCRS items in a control group; according to those authors, the probable explanation for their finding was that individuals might have had the ability to mask their difficulties or hide them from relatives.³⁸ This finding may reflect poor observation or the lack of opportunities to observe.

Further examination of the PCRS-R-BR items revealed that in the group of patients with mild TBI, items assessing financial abilities, episodic memory and ability to argue with others had the same pattern as the one described above. The analysis of items in the group of patients with moderate/severe TBI revealed the same pattern only in the item investigating the ability to remember people's names. These findings suggest that the relatives of the group of patients with mild TBI are more susceptible to overestimating patient abilities than those of the group of patients with moderate/severe TBI. At the same time, the answers given by patients with moderate/severe TBI indicated a lack of self-awareness in more items, according to the item discrepancy score. Some items in which the scores of relatives and patients with moderate/severe TBI differed significantly (items 1, 2, 7, and 13) were the same as the ones found in a study with a general sample of patients with TBI using the original PCRS.³⁹ Abilities of planning, inhibition, semantic memory and theory of mind

are expected to be impaired in terms of self-awareness. In addition, our findings support that severity is one of the main factors associated with self-awareness in TBI,⁴⁰ as the groups with the most severe TBI are usually less aware of their cognitive impairments than those with milder conditions.³⁸

Final considerations

The study draws attention to the importance of carefully adapting assessment instruments to cultural and linguistic variations. Several changes described in this study were essential for the application of the PCRS-R-BR to individuals in the Brazilian culture. Limitations of this study were the lack of a healthy control group, lack of further analysis and data collection to investigate other PCRS-R-BR validity criteria, and lack of studies to compare findings, as this was the first investigation to evaluate this tool. In addition, our scoring system with “not applicable” option may have influenced results; however this score option was infrequent and our findings are in agreement with previous literature, as previously cited. The adaptation of the PCRS-R-BR should improve neuropsychological assessment using functional and ecological measures – one of the main concerns of contemporary neuropsychology. The present findings may also contribute to the establishment of functional diagnoses and rehabilitation plans for different clinical populations. In addition, the PCRS-R-BR may also be used as an outcome and follow-up measure, especially in rehabilitation settings. Future studies should investigate the correlations of PCRS-R-BR data with behavioral performance measures of EF, attention, and memory, the effect of sociocultural variables on PCRS-R-BR results, and brain activity associated with self-awareness in different contexts.

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Appendix 1

PATIENT COMPETENCY RATING SCALE – VERSÃO BRASILEIRA (PCRS-R-BR) – PARA PACIENTES

O questionário abaixo pede que você avalie a sua capacidade de fazer algumas coisas no dia a dia. As perguntas são relacionadas ao seu funcionamento após a lesão cerebral. Em cada pergunta, você deve julgar o quanto de dificuldade você tem para realizar uma atividade e apontar a resposta que explica melhor a sua opinião.

Perguntas	Não consegue	Muito difícil	Faz com alguma dificuldade	Razoavelmente fácil	Faz com facilidade	Não se aplica
1) Quanta dificuldade você tem para preparar as suas refeições?						
2) Quanta dificuldade você tem em cuidar das suas finanças?						
3) Quanta dificuldade você tem em comparecer a compromissos sem atrasos?						
4) Quanta dificuldade você tem em iniciar conversas em um grupo?						
5) Quanta dificuldade você tem em se manter envolvido(a) em atividades obrigatórias que tem que terminar mesmo quando está se sentindo cansado(a) ou entediado(a)?						
6) Quanta dificuldade você tem para lembrar o que você comeu no jantar ontem?						
7) Quanta dificuldade você tem de lembrar o nome das pessoas que você vê frequentemente?						
8) Quanta dificuldade você tem em se lembrar dos seus horários e compromissos do dia?						
9) Quanta dificuldade você tem em pedir ajuda quando está confuso(a) para resolver um problema ou quando não entende alguma coisa?						
10) Quanta dificuldade você tem em se ajustar a mudanças que acontecem de uma hora para outra? Por exemplo, você está se organizando para uma atividade e de repente acontecem mudanças de planos. Quanta dificuldade você tem em lidar com isso?						
11) Quanta dificuldade você tem em defender o seu ponto de vista quando está conversando com as pessoas?						
12) Quanta dificuldade você tem em agir de modo esperado quando está entre amigos? Por exemplo, cuidando para não fazer coisas que as pessoas não gostam.						
13) Quanta dificuldade você tem em perceber que algo que disse ou fez chateou outra pessoa?						
14) Quanta dificuldade você tem em planejar as suas atividades diárias?						
15) Quanta dificuldade você tem em entender e aprender novas tarefas?						
16) Quanta dificuldade você tem em cumprir de maneira efetiva as suas responsabilidades diárias?						
17) Quanta dificuldade você tem em se manter concentrado(a) em uma atividade ou tarefa? Por exemplo, quando quer ver um capítulo de novela até o final ou assistir um programa de televisão até o final.						

Appendix 2

PATIENT COMPETENCY RATING SCALE – VERSÃO BRASILEIRA (PCRS-R-BR) – PARA FAMILIARES

O questionário abaixo pede que você avalie a capacidade do seu(a) familiar, amigo(a) ou cliente de fazer algumas coisas no dia a dia. As perguntas são relacionadas ao funcionamento dele(a) no dia-dia ou após a lesão cerebral. Em cada pergunta, você deve julgar o quanto de dificuldade ele(a) tem para realizar uma atividade e marcar a resposta que explica melhor a sua opinião.

Perguntas	Não consegue	Muito difícil	Faz com alguma dificuldade	Razoavelmente fácil	Faz com facilidade	Não se aplica
1) Quanta dificuldade ele(a) tem para preparar as próprias refeições?						
2) Quanta dificuldade ele(a) tem em cuidar das próprias finanças?						
3) Quanta dificuldade ele(a) tem em comparecer a compromissos sem atrasos?						
4) Quanta dificuldade ele(a) tem em iniciar conversas em um grupo?						
5) Quanta dificuldade ele(a) tem em se manter envolvido(a) em atividades obrigatórias que tem que terminar mesmo quando está se sentindo cansado(a) ou entediado(a)?						
6) Quanta dificuldade ele(a) tem para lembrar o que ele(a) comeu no jantar ontem?						
7) Quanta dificuldade ele(a) tem em lembrar o nome das pessoas que ele(a) vê frequentemente?						
8) Quanta dificuldade ele(a) tem em lembrar dos horários e compromissos do dia?						
9) Quanta dificuldade ele(a) tem em pedir ajuda quando está confuso(a) para resolver um problema ou quando não entende alguma coisa?						
10) Quanta dificuldade ele(a) tem em ajustar-se a mudanças que acontecem de uma hora para outra? Por exemplo, ele(a) está se organizando para uma atividade e de repente acontecem mudanças de planos. Quanta dificuldade ele(a) tem em lidar com isso?						
11) Quanta dificuldade ele(a) tem em defender um ponto de vista quando está conversando com as pessoas?						
12) Quanta dificuldade ele(a) tem em agir de modo esperado quando está entre amigos? Por exemplo, cuidando para não fazer coisas que as pessoas não gostam.						
13) Quanta dificuldade ele(a) tem em perceber que algo que disse ou fez chateou outra pessoa?						
14) Quanta dificuldade ele(a) tem em planejar as atividades diárias?						
15) Quanta dificuldade ele(a) tem em entender e aprender novas tarefas?						
16) Quanta dificuldade ele(a) tem em cumprir de maneira efetiva as responsabilidades diárias?						
17) Quanta dificuldade ele(a) tem em se manter concentrado(a) em uma atividade ou tarefa? Por exemplo, quando quer ver um capítulo de novela até o final ou assistir um programa de televisão até o final.						