

# Cross-Cultural Adaptation and Validation for Portuguese (Brazilian) of the Pictorial Representation of Illness and Self Measure Instrument in Orofacial Pain Patients

## Alexandre César Lima-Verde, MSc

Graduate Student  
São Leopoldo Mandic Dental  
Research Center  
Campinas, Brazil

## Daniel Humberto Pozza, PhD

Professor  
Department of Experimental Biology  
Medical School and IBMC  
University of Porto  
Porto, Portugal

## Luciane Lacerda Franco Rocha

Rodrigues, PhD  
Professor  
São Leopoldo Mandic Dental  
Research Center  
Campinas, Brazil

## Ana Miriam Velly, DDS, MS, PhD

Assistant Professor  
Faculty of Dentistry  
McGill University  
Montreal, Quebec, Canada

## Antônio Sérgio Guimarães, PhD

Head, TMD and Orofacial Pain Clinic  
São Leopoldo Mandic Dental  
Research Center  
Campinas, Brazil

## Correspondence to:

Prof Antônio Sérgio Guimarães  
TMD and Orofacial Pain Clinic  
São Leopoldo Mandic Dental  
Research Center  
R. José Rocha Junqueira, 13  
Campinas, 13045-755 Brazil  
Email: asgadm@gmail.com

***Aims:** To translate the Pictorial Representation of Illness and Self Measure (PRISM) instrument from German to Portuguese (Brazilian) and adapt it to the Brazilian cultural context, and then assess its reliability and validity in orofacial pain patients. **Methods:** The PRISM was translated to Portuguese then back-translated to German. The translated PRISM was evaluated by a multidisciplinary committee and administered as a pre-test to 30 Portuguese-speaking orofacial pain patients. Psychometric properties were obtained after testing 116 orofacial pain patients. Validity was obtained through correlation analyses of scores obtained from PRISM and other psychometric tests, including the Numerical Pain Scale (NPS), Insomnia Severity Index (ISI), and Hospital Anxiety and Depression Scale (HAD). **Results:** The adapted instrument showed high levels of reliability, proven by means of the test-retest procedure, and calculation of the Intraclass Correlation Coefficient (ICC = 0.991). Significant correlations were found between PRISM and the other tests. Correlation with NPS was moderate (-0.42), whereas correlations with ISI (-0.24), HAD-anxiety (-0.25), and HAD-depression (-0.22) were weak. **Conclusion:** The cross-cultural adaptation process of PRISM was successful and the adapted version offers reliable and valid psychometric properties in the Brazilian context. J OROFAC PAIN 2013;27:271-275. doi: 10.11607/jop.1070*

**Key words:** cultural adaptation, orofacial pain, Pictorial Representation of Illness and Self Measure, PRISM, reliability, suffering, validation studies

Patients who experience orofacial pain as a chronic pain condition typically present distress and suffering that have an important impact on their quality of life (QoL).<sup>1</sup> Thus, suffering is an important measure in clinical and epidemiologic studies,<sup>2,3</sup> whereas the patient's perception of his or her own condition plays an increasingly important role.<sup>4</sup>

To this day, little has been published in the medical and psychological literature on suffering in orofacial pain patients.<sup>5</sup> To effectively treat patients, it is essential to assess and understand the impact of their illness on them.<sup>6</sup> Developing a variety of instruments that assess the impact of suffering on health and QoL represents a step in this direction.<sup>7</sup> Many of the questionnaires that assess levels of illness-related suffering, however, are time-consuming and difficult to interpret. To address these weaknesses, the Pictorial Representation of Illness and Self Measure (PRISM) was proposed by Büchi et al in 1998.<sup>6</sup> PRISM is an intuitive, graphic, and pictorial instrument that takes less than 5 minutes to complete.<sup>8</sup> In the PRISM task, patients are asked to visually represent the extent to which their pain

occupies their life. Patients do so by placing a red disk, that represents pain, on the PRISM board. A major advantage of the PRISM is its capacity not to be influenced by cultural differences.<sup>5,9</sup>

PRISM has been validated to measure levels of suffering in patients with chronic non-cancer pain,<sup>10</sup> such as orofacial pain.<sup>3</sup> It has also been validated to measure suffering in patients with various health conditions, such as chronic obstructive pulmonary disease,<sup>11</sup> systemic lupus erythematosus,<sup>12</sup> and dermatologic disease requiring hospitalization,<sup>9,13</sup> as well as in people who have experienced events associated with great suffering, such as the loss of a premature child<sup>14</sup> or posttraumatic situations.<sup>15</sup>

Based on the advantages of PRISM and the lack of such a valid and reliable instrument in Portuguese, the aim of this study was to translate the PRISM instrument from German to Portuguese (Brazilian) and adapt it to the Brazilian cultural context, and then assess its reliability and validity by using orofacial pain patients.

## Materials and Methods

### Study Design and Population

This cross-sectional prospective study was conducted in the dental clinic of the São Leopoldo Mandic School of Dentistry and Dental Research Center in Campinas, Brazil, from February 2011 to January 2012. The study protocol was approved by the Ethical Committee of the São Leopoldo Mandic's Dental Research Center (protocol no. 2010/0309). All subjects signed an informed consent form prior to filling out the questionnaires.

Patients aged 18 or more with diagnosed orofacial pain between February 2011 and January 2012 were eligible to participate. Patients who were being treated for ongoing orofacial pain or unable to understand or answer the questions were not included in the present study.

The quantitative measure derived from PRISM is the Self-Illness Separation (SIS). The SIS is the distance between the centers of the red disk and disks representing areas of the self. The possible range for the SIS is 0 to 27 cm, with smaller values representing greater suffering.<sup>5,16</sup>

### Translation and Cross-Cultural Adaptation

Permission was obtained to translate PRISM from Dr S. Büchi, the researcher who originally developed this instrument. To maintain the quality of the cross-cultural adaptation process, PRISM was translated

according to the internationally standardized methodological rules<sup>17,18</sup>: (1) PRISM forward translation into Portuguese by two independent translators (T1 and T2); (2) synthesis of the translations (T12); (3) back-translation into German by two independent translators (RT1, RT2); (4) multidisciplinary committee's evaluation; and (5) pre-test.

PRISM forward translation was conducted by two Brazilians fluent in the German language. One of the translators is a dentist aware of the study's objectives, while the other holds a bachelor's degree in literature with specialization in translation. The two translated versions were compared and synthesized into a single document (T12), which was then back-translated to German. The Portuguese to German translation was carried out by two Swiss citizens fluent in Portuguese who were currently living in Brazil. Both back-translations were revised and synthesized into one final version (RT12). The final back-translation version demonstrated grammatical and semantic equivalence with the original instrument. Up to this step, T12 was accepted as the PRISM Portuguese translation. Cultural and idiomatic equivalence of this version was analyzed by a bilingual multidisciplinary committee. After the committee's revision, a pilot version was obtained to pre-test 30 orofacial pain patients, 27 with chronic pain (90%) and 3 with acute pain (10%). Participants were asked to perform the PRISM task and give feedback on the instrument. Suggestions were presented to the multidisciplinary committee, and the final version was approved.

### Reliability and Validity

Reliability was assessed using test-retest. The PRISM was administered to the same group of patients (same place and conditions,  $n = 30$ ) on two separate occasions at an interval of 3 days in order to observe the consistency in the measure's repetitions (temporal stability).

Content validity was performed by assessing the associations between PRISM scores with those of previously validated and established instruments. All of the 30 patients scored PRISM equally as before, validating the pre-test data. Thus new subjects were recruited until a sample of over 100 ( $n = 116$ ) was reached to validate the test-retest study. The selected instruments were the Numeric Pain Scale (NPS)<sup>19</sup> (to assess current pain), Insomnia Severity Index (ISI),<sup>20</sup> and the affective symptoms by Hospital Anxiety and Depression Scale (HAD).<sup>21</sup> According to several studies, PRISM is a valid instrument to assess the suffering related to pain, sleep, and affective symptoms.<sup>5,6,8-10,12-15,22</sup>

**Table 1** Quantitative Variables for the 116 Orofacial Pain Patients

Variable	Mean $\pm$ SD	Median	Min–Max	CI
Age	44.4 $\pm$ 13.1	44	18–74	2.4
SIS	8.67 $\pm$ 7.52	7	0–26.5	1.37
NPS	6.68 $\pm$ 2.19	7	0–10	0.40
ISI	10.45 $\pm$ 6.54	10.5	1–8	1.19
HAD-A	8.38 $\pm$ 4.38	8	0–20	0.80
HAD-D	6.91 $\pm$ 4.34	6	0–19	0.79

SIS, Self-Illness Separation; NPS, Numeric Pain Scale; ISI, Insomnia Severity Index; HAD-A, Hospital Anxiety and Depression Scale, Anxiety; HAD-D, Hospital Anxiety and Depression Scale, Depression; SD, standard deviation; CI, confidence interval.

## Statistical Analysis

PRISM reliability was tested by means of the test-retest procedure and expressed by the Intraclass Correlation Coefficient (ICC). Pearson correlations were conducted to quantify the relationship between PRISM and the other validated variables. The confidence level was 95%. All statistical analyses were performed using the Statistical Package for Social Sciences Version<sup>15</sup> and Minitab.<sup>14</sup>

## Results

One hundred sixteen orofacial pain patients (77.6% female, 22.4% male) were included in the study. The mean age of the sample was 44.4 years, and 61.2% were married. The majority (68.1%) of the participants had a medium education level, 22.4% had a basic education level, and 9.5% were either university students or had graduated from university.

The PRISM is an instrument that uses mainly graphics and visuals, therefore the potential for mistranslation is minimal (T12). The pretesting searched for possible misunderstanding by the patients. After reading the instructions, patients were interviewed to identify any possible difficulties with the use of PRISM. According to the vast majority of the participants, PRISM was easy to understand. This was the case after participants were given an example proposed on the original instructions. During the pre-test procedure, only 2 out of 30 participants did not understand the task. The scores obtained in the questionnaires, scales, and PRISM are shown in Table 1.

The mean current pain on the NPS (0 to 10) was 6.68. The mean score of the ISI (scale varies from

**Table 2** Distribution of the Patients' Main Complaints (Multiple Responses Possible)

Pain localization	% of patients
Facial pain	44.6
Headache	25.0
TMJ click	19.0
TMJ pain	17.2
Ear pain	10.3
Tinnitus	6.0
Bruxism	4.3
Pain in the neck	3.4
Dental pain	2.6
Others (sum of different oral complaints)	10.2

TMJ, temporomandibular joint.

0 to 28) was 10.45. The HAD-anxiety mean score was 8.38 (scale varies from 0 to 20) and the HAD-depression mean score was 6.91 (scale varies from 0 to 19). The minimum value for the SIS was 0, while the maximum was 26.5 cm. The patients' main complaints can be seen in Table 2. The most prevalent complaint was facial pain (pain in the masseter or temporal region), which was present in 46.6% of the subjects ( $P < .05$ ).

Analyzing the reliability of PRISM revealed near identical scores when comparing the mean values in the test (7.11) and in the retest (7.05), showing that the measure is reliable. Test-retest reliability was assessed by using the ICC, and was considered excellent (0.99).

PRISM correlated significantly with all variables. The correlations were negative, indicating that the higher the PRISM score, the lower the other variable's scores and vice-versa. However, despite being significant, correlations between PRISM and NPS were moderate ( $-0.42$ ,  $P < .001$ ), and correlations between PRISM and ISI ( $-0.24$ ,  $P = .009$ ), HAD-A ( $-0.25$ ,  $P = .006$ ) and HAD-D ( $-0.22$ ,  $P = .019$ ) were weak.

## Discussion

The results of this study demonstrated that the PRISM task may help evaluate suffering in Brazilian individuals with orofacial pain. The cross-cultural PRISM adaptation to the Brazilian context followed methodological criteria well established in the literature<sup>17,18</sup> and was considered easy to perform. This finding could be related to the fact that PRISM is minimally influenced by cultural differences due to its more intuitive, graphic, and pictorial nature.<sup>5,8</sup>

Every PRISM validation study, including studies with orofacial pain patients,<sup>22</sup> has shown that a low SIS score is related to a lower quality of life, greater pain catastrophizing, and greater perceived pain and suffering, besides a greater interference in the daily life aspects.<sup>5,6,8,10,15,22</sup> In general, informal comments from the patients after completing the PRISM task were consistent with where they positioned the red disk. According to the subjects, this position was more related to the burden of suffering, perceived intrusion, and threat brought by their pain rather than to the intensity of this pain, which is the aim of the original concept of suffering proposed by Cassel.<sup>23</sup> Despite the possibility of a “cognitive bias” and the absence of a gold-standard measure to quantify suffering, data consistency in all validation reports<sup>5,6,8,10,15,22</sup> suggest that PRISM facilitates communication by allowing illness to be “mapped” in a biopsychosocial context.

In the present investigation, the mean score found in the test was statistically identical to the mean score of the retest, which means that the measures are reliable across time. PRISM was used in the first consultation and was repeated 3 days after. There was no interference in the pain process, since patients had not received treatment instructions during that time frame. The reliability of the measures was also assessed using the ICC, which was highly significant (0.99). Previous PRISM studies found analogous ICC values (0.95,<sup>5,10</sup> 0.85<sup>15</sup>). Furthermore, in the current work, statistically significant correlations were found between PRISM and all proposed tests in the methodology. The moderate correlation found between PRISM and NPS in the present study (−0.42) was very close to the correlations found in other PRISM validation studies<sup>6,10</sup> that used similar methodologies (−0.48 and −0.46, respectively). Streffer et al,<sup>22</sup> using the PRISM in paper-and-pencil version, found a moderate correlation of −0.41 in the ISI index. In the current study, a significant correlation between PRISM and ISI was also found, but according to Pearson’s correlation it was considered weak. These findings corroborate the fact that suffering related to pain negatively influences the quality and quantity of sleep.

The results of the present study (−25% for anxiety and −21% for depression) agree with previous findings of significant but weak correlations between PRISM and HAD-anxiety (−21%) and HAD-depression (−21%) in orofacial pain patients.<sup>22</sup> Thus, PRISM may not be useful to assess these symptoms in orofacial pain patients. Indeed, PRISM measures seem to be more related to pain and depression than

to the overall QoL measures, illness activity, or functional impairment.<sup>8</sup> PRISM correlations with diverse variables differ from one condition to the other in several validation studies.<sup>5,6,8,10,15,22</sup>

In accordance with the previous studies,<sup>22</sup> the main limitation of the PRISM cross-cultural adaptation seems to be the weak correlation of the instrument with the HAD index. However, the objective of the present study was not to correlate the PRISM with the HAD index; it was to verify the concordance with previous studies,<sup>22</sup> where this correlation was also weak. Although the instrument demonstrated easy application and acceptability, there were some other limitations in the way the instructions were given to the participants. Most patients who seek health care in universities and research centers in Brazil have a low educational level. This could explain why the initial comprehension of the PRISM task was somewhat difficult. Yet, after being given the suggested example from the original instructions, all participants could easily figure out the PRISM task. Some flexibility in the conduct of the PRISM task was allowed in order to accommodate an individual’s educational level, thereby increasing the verbal interaction in the example proposed in the instructions.

According to Mühleisen et al,<sup>9</sup> weaknesses of the PRISM instrument include its dependence on an interviewer, which precludes patients from filling out questionnaires anonymously and in private. Nevertheless, this direct patient-clinician interaction makes PRISM a unique instrument that facilitates communication.<sup>8,13</sup> Another point to be considered is the use of disks and the metal board, a patented product, which can limit the applicability spectrum in developing countries due to economic reasons. Free software recently has been developed for PRISM online, which may help expand the applicability of the instrument.<sup>24</sup> However, it requires patient education and adequate computer availability, affordability, and accessibility.

According to the results of the present study, a new Brazilian PRISM instrument has proven to have considerable reliability and significant validity in an orofacial pain population. This instrument will contribute to an innovative tool in scientific research or clinical practice, offering a quantitative health-related quality of life measure. As proposed by Streffer et al,<sup>22</sup> future research should expand this initiative and determine if PRISM may be useful in stratifying orofacial pain patients in need of conventional primary care or of a more specialized and multidisciplinary care.

## References

- Saxena S, Orley J. Quality of life assessment: The world health organization perspective. *Eur Psychiatry* 1997;12:263s–266s.
- Faden R, Leplege A. Assessing quality of life. Moral implications for clinical practice. *Med Care* 1992;30:166–175.
- Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Ann Intern Med* 1993;118:622–629.
- Denton F, Sharpe L, Schrieber L. PRISM: Enmeshment of illness and self-schema. *Psychother Psychosom* 2004;73:57–63.
- Büchi S, Buddeberg C, Klaghofer R, et al. Preliminary validation of PRISM (Pictorial Representation of Illness and Self Measure)—A brief method to assess suffering. *Psychother Psychosom* 2002;71:333–341.
- Büchi S, Sensky T, Sharpe L, Timberlake N. Graphic representation of illness: A novel method of measuring patients' perceptions of the impact of illness. *Psychother Psychosom* 1998;67:222–225.
- Bowling A. *Measuring Health: A Review of Quality of Life Measurement Scales* ed 2. Buckingham, UK: Open University Press, 1997.
- Büchi S, Sensky T. PRISM: Pictorial Representation of Illness and Self Measure. A brief nonverbal measure of illness impact and therapeutic aid in psychosomatic medicine. *Psychosomatics* 1999;40:314–320.
- Mühleisen B, Büchi S, Schmidhauser S, Jenewein J, French LE, Hofbauer GF. Pictorial Representation of Illness and Self Measure (PRISM): A novel visual instrument to measure quality of life in dermatological inpatients. *Arch Dermatol* 2009;145:774–780.
- Kassardjian CD, Gardner-Nix J, Dupak K, Barbati J, Lam-McCulloch J. Validating PRISM (Pictorial Representation of Illness and Self Measure) as a measure of suffering in chronic non-cancer pain patients. *J Pain* 2008;9:1135–1143.
- Büchi S, Brändli O, Klingler K, Klaghofer R, Buddeberg C. [Inpatient rehabilitation in inpatients with chronic obstructive lung diseases (COPD): Effect on physical capacity for work, psychological wellbeing, and quality of life, in German]. *Schweiz Med Wochenschr* 2000;130:135–142.
- Büchi S, Villiger P, Kauer Y, Klaghofer R, Sensky T, Stoll T. PRISM (Pictorial Representation of Illness and Self Measure)—A novel visual method to assess the global burden of illness in patients with systemic lupus erythematosus. *Lupus* 2000;9:368–373.
- Tondury B, Muehleisen B, Ballmer-Weber BK, et al. The Pictorial Representation of Illness and Self Measure (PRISM) instrument reveals a high burden of suffering in patients with chronic urticaria. *J Investig Allergol Clin Immunol* 2011;21:93–100.
- Büchi S, Morgeli H, Schnyder U, et al. Grief and post-traumatic growth in parents 2–6 years after the death of their extremely premature baby. *Psychother Psychosom* 2007;76:106–114.
- Wittmann L, Schnyder U, Büchi S. PRISM (Pictorial Representation of Illness and Self Measure): A new method for the assessment of suffering after trauma. *J Trauma Stress* 2012;25:94–97.
- Klis S, Vingerhoets AJJM, de Wit M, Zandbelt N, Snoek FJ. Pictorial Representation of Illness and Self Measure Revised II (PRISM-RII)—A novel method to assess perceived burden of illness in diabetes patients. *Health and Quality of Life Outcomes* 2008;6:104.
- Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine (Phila Pa 1976)* 2000;25:3186–3191.
- Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. *J Clin Epidemiol* 1993;46:1417–1432.
- Huskisson EC. Measurement of pain. *Lancet* 1974;2:1127–1131.
- Bastien CH, Vallieres A, Morin CM. Validation of the Insomnia Severity Index as an outcome measure for insomnia research. *Sleep Med* 2001;2:297–307.
- Kino K, Sugisaki M, Ishikawa T, Shibuya T, Amagasa T, Miyaoka H. Preliminary psychologic survey of orofacial outpatients. Part 1: Predictors of anxiety or depression. *J Orofac Pain* 2001;15:235–244.
- Streffer ML, Büchi S, Morgeli H, Galli U, Ertlin D. PRISM (pictorial representation of illness and self measure): A novel visual instrument to assess pain and suffering in orofacial pain patients. *J Orofac Pain* 2009;23:140–146.
- Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med* 1982;306:639–645.
- Büchi S. PRISM on line: <http://www.prism-coop.ch/en/index.htm>. Accessed June 3, 2013.