

# PRISM (Pictorial Representation of Illness and Self Measure): A Novel Visual Instrument to Assess Pain and Suffering in Orofacial Pain Patients

## Marie-Luise Streffer, MD, DMD

Resident  
Department of Oral and Maxillofacial  
Surgery  
University Hospital of Zurich

## Stefan Büchi, MD

Clinical Director  
Unit for Psychosomatics  
Clinic for Psychotherapy and  
Psychosomatics "Hohenegg"  
Meilen, Switzerland

## Hanspeter Mörgeli, PhD

Senior Researcher  
Department of Psychiatry  
University Hospital of Zurich

## Ursula Galli, PhD

Chief Psychologist  
Clinic for Masticatory Disorders,  
Removable Prosthodontics, Geriatric  
and Special Care Dentistry  
University of Zurich

## Dominik Ettlin, MD, DMD

Director  
Orofacial Pain Service  
Clinic for Masticatory Disorders,  
Removable Prosthodontics, Geriatric  
and Special Care Dentistry  
University of Zurich

## Correspondence to:

Dr Dominik Ettlin  
Clinic for Masticatory Disorders,  
Removable Prosthodontics, Geriatric  
and Special Care Dentistry  
University of Zurich  
Plattenstrasse 11  
CH-8028 Zurich, Switzerland  
Email: ettlin@zzmk.uzh.ch

**Aims:** To use PRISM (Pictorial Representation of Illness and Self Measure), a visual instrument that has recently been developed and validated to assess suffering in patients with chronic physical illness, in orofacial pain patients and test for associations of PRISM with established assessment tools for pain, affective symptoms, and sleep. Of particular interest was the utility of PRISM as a screening tool for severely suffering patients. **Methods:** One hundred and two orofacial pain patients recruited from a specialized outpatient service completed a questionnaire-based survey, including established assessment tools: the Visual Analog Scale (VAS), Graded Chronic Pain Scale (GCPS), the Hospital Anxiety and Depression Scale (HADS), and the Insomnia Severity Index (ISI), as well as a paper and pencil version of PRISM. **Results:** Of the 102 patients who submitted the clinical questionnaire, 74 performed the PRISM-test (response rate: 72%). PRISM scores correlated strongly with all subscores of pain (measured by GCPS) and sleep (measured by ISI). Further, a trend was observed in the correlation with affective symptoms measured by the HADS. PRISM could readily detect patients with high, pain-related suffering. **Conclusion:** These data add support to the hypothesis that the PRISM task in its paper and pencil version is measuring the burden of suffering. The clinical utility of this simple graphic tool therefore lies in its potential to alert clinicians to a high burden of suffering and thus it may help to identify orofacial pain patients who may benefit from more comprehensive assessment and treatment. Prospective studies are needed to clarify this claim. *J OROFAC PAIN* 2009;23:140-146

**Key words:** anxiety, depression, orofacial pain, PRISM, sleep, suffering

Pain and related suffering are globally relevant topics for health-care providers.<sup>1-4</sup> For orofacial pain, prevalence rates between 10% to 16% have been reported among adults.<sup>1-3</sup> Most studies have described a female to male gender ratio of 2:1, and a higher incidence among younger adults.<sup>4</sup> Pain in the orofacial region may cause severe distress and decreased quality of life.<sup>1,2</sup> Lack of early comprehensive diagnosis and therapy can result in the development of chronic pain and increased suffering.<sup>5-8</sup>

For optimal biopsychosocial patient management, clinicians need to understand not only the patient's symptoms but, equally important, the impact of symptoms on the individual. Of primary importance is early identification of those subjects requiring interdisciplinary assessment and treatment.<sup>9</sup> However, current questionnaires for this purpose are few and commonly require patients to answer long lists of questions with uncertain relevance.<sup>10,11</sup>

One instrument mainly used for research purposes is the Graded Chronic Pain Scale (GCPS),<sup>12</sup> a questionnaire assessing pain intensity as well as pain interference with the activities of daily living. The GCPS has proven to be a valid screening instrument to identify orofacial pain patients with significant behavioral and psychological pain dysfunction who are at risk for poor outcomes.<sup>10</sup> However, to our knowledge, it is not widely used in dental offices in Europe until now. One possible reason may be that dentists are unfamiliar in the use of questionnaires.

Graphic systems such as pictures, charts, and graphs often facilitate communication, especially in the medical context. Some of the most established graphic tools in medicine are pain drawings and visual analog scales (VAS) widely used to assess location and characteristics of pain. PRISM (Pictorial Representation of Illness and Self Measure) is a novel, nonverbal visualization technique developed and validated to measure the patient's perceived burden of illness-related suffering.<sup>13–15</sup> It has recently been validated as a measure of suffering in chronic pain patients.<sup>16</sup> Analogous to VAS, PRISM yields a quantitative measure, Self Illness Separation (SIS), that reflects the person's perception of the intrusiveness and controllability of the illness or its symptoms.<sup>14,17,18</sup> It is validated to assess suffering in chronic diseases (rheumatoid arthritis, chronic obstructive pulmonary disease, diabetes mellitus, or systemic lupus erythematosus) as well as other events associated with an extraordinary burden of suffering, such as the loss of a premature child.<sup>13,18</sup> PRISM was originally developed as an interactive tool for daily clinical practice but recently a "paper and pencil version" has also been validated.<sup>19,20</sup>

The aim of this pilot study was to use PRISM in orofacial pain patients and test for associations of PRISM with established assessment tools for pain, affective symptoms, and sleep. Of particular interest was the utility of PRISM as a screening tool for severely suffering patients.

## Materials and Methods

### Procedure

Data used in this report were derived from patients referred to the interdisciplinary orofacial pain consulting service at the Clinic for Masticatory Disorders, Removable Prosthodontics, Geriatric and Special Care Dentistry, University of Zurich, Switzerland. In order to obtain a comprehensive

understanding of their pain symptoms and related impact, all patients were asked to complete a questionnaire at home and to bring it to their first clinic appointment. This questionnaire included several validated tests and scales, as well as detailed questions concerning preceding clinical investigations and therapies, current medication, self-treatment modalities, and graphic representation of pain localization. For this report, demographic data, PRISM, GCPS, Hospital Anxiety and Depression Scale (HADS), and the Insomnia Severity Index (ISI) were used (see below). GCPS, HADS, and ISI were chosen to test the construct validity of the PRISM. Based on previous studies which have shown PRISM to be a valid tool for assessing those domains, we hypothesized that in this study the PRISM test would show a moderate to high association with these instruments. The questionnaires of 102 consecutive patients being assessed between January and December 2006 were included in the study. Inclusion criteria were: age between 16 and 80 years and proficiency in the German language. The study protocol was approved by the Ethical Committee of the Medical Council of the Canton of Zurich. All subjects signed an informed consent form prior to filling out the questionnaire.

### PRISM

PRISM has been developed as an interactive visualization tool to measure suffering and has been successfully validated.<sup>13,14,17–20</sup> The original PRISM consisted of a white metal board measuring 210 × 297 mm (A4 format) with a fixed yellow disc (7 cm diameter) at the bottom right-hand corner, representing the patient's self. Patients were given a red 5 cm diameter mobile magnetic disc with the instruction to imagine this disc to represent their illness. They were asked to place this red disc on the metal board after receiving the following instruction: "Where would you put the illness disc to show its importance in your life at the moment?" The main quantitative measure derived from PRISM is the SIS, ie, the distance in centimeters, between the centers of the "illness" and the "self" discs.

The unique property of PRISM is its focus on the individual relationship of a patient with his or her pain, assessed by the SIS value. Qualitative exploration in 138 non-cancer chronic pain patients distances detected three properties of the individual meaning of SIS<sup>16</sup>: (1) feeling of subjective pain control, (2) pain-related loss of relevant personal life aspects (eg, family or work), and (3) pain intensity. The PRISM/SIS is thus related to, yet conceptually

different from, VAS. This difference can best be illustrated in individual case analyses in which pain relief by opioids reduced VAS pain measures, but paradoxically increased patients' suffering (ie, decrease of SIS).<sup>14</sup> Qualitative analysis detected that in these patients, adverse effects of opioids (eg, fatigue, decreased concentration) had marked effects on patients' perception of control and reduced their capacity for cognitive work on the computer so much that these adverse drug effects exceeded the benefit of pain reduction.

In the present study, the recently validated modified paper and pencil version of PRISM was used.<sup>19,20</sup> In the questionnaire, the square containing the "Self" circle measured 90 × 65 mm and the radius of the "Self" circle was 1.5 cm. The test and its instructions are described in Fig 1. The distance between the "Self" circle and the cross representing the pain was termed the Self-Pain-Separation (SPS), which in the graph could range from 0 to 8.5 cm (see Fig 1).

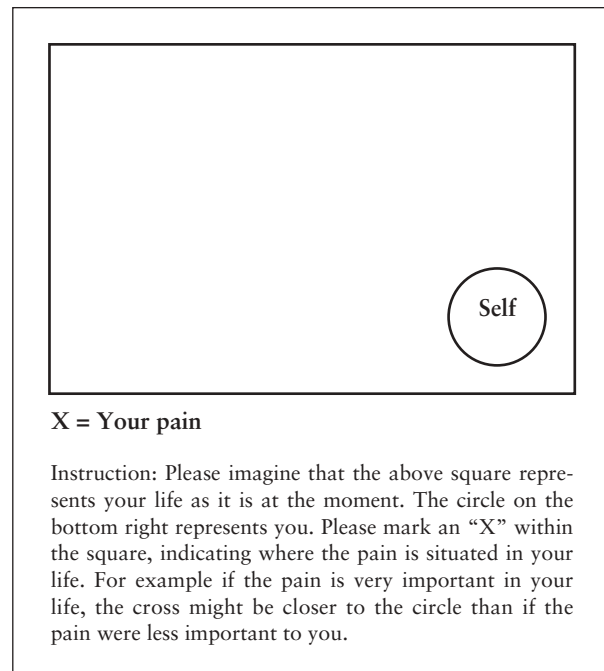
The PRISM task allows for PRISM-inself and PRISM-outself patients to be distinguished. Analogous to other studies,<sup>13,17,21</sup> patients who place the cross in their "Self" circle (PRISM-inself patients, eg, SPS ≤ 1.5 cm) can be considered as belonging to the group with a high burden of suffering.

## GCPS

The GCPS is an established instrument with seven items for investigating pain and its impact on daily activities.<sup>12</sup> It includes questions on pain intensity and pain interference with daily life. There are three subscales: GCPS-disability (GCPS-DS), GCPS-pain intensity (GCPS-PI), and GCPS-disability points (GCPS-BP, not used in the analyses). The answers are standardized on 11-point numeric rating scales and rated in four hierarchical classes. Grade I: low disability/low intensity, Grade II: low disability/high intensity, Grade III: high disability/moderately limiting, Grade IV: high disability/severely limiting.

## ISI

The ISI is a widely used screening and evaluation tool for insomnia.<sup>7</sup> It has been successfully validated in patients with physical illness.<sup>22</sup> It includes six questions addressing sleep quality, sleep quantity, and the impact of insomnia on daily life activities. The answers are standardized on five-point numeric rating scales. The range of the summary score is 0 to 28 with a cutoff at 8, above which patients are considered to be suffering from clinical insomnia.<sup>7</sup>



**Fig 1** Paper and pencil version of PRISM used in this investigation.

## HADS

The HADS<sup>23</sup> is a self-report measure to detect depression and anxiety disorder in patients with somatic disease. In this study, the validated German translation was used.<sup>24</sup> Depression and anxiety are each assessed by seven items (range 0 to 3). For both depression and anxiety, scale scores up to 7 are considered normal, values between 8 and 10 indicate possible anxiety or depression, and scores above 10 indicate probable anxiety and/or depression disorder.

## Statistical Analysis

All data obtained from the questionnaires were analyzed using the Statistical Package for Social Sciences Version 15.0 (SPSS Inc, Chicago, IL). Pearson's correlation coefficients were calculated between PRISM and GCPS subscales HADS-A and HADS-D (which score anxiety and depression, respectively), and the ISI to test for the correlation between these measures.  $P \leq .05$  indicated statistical significance. The differences in these subscales between PRISM-inself and PRISM-outself patients were assessed by *t* tests.

**Table 1** Characteristics of the Sample (n = 102)

Variable	Value
Gender (no. of patients)	
Female	81 (78.4%)
Male	21 (21.6%)
Age of patients (y)	
Range	17–76
Mean	44.3
SD	15.3
Pain localization (no. of patients)*	
Dental pain	44 (44.9%)
Facial pain	61 (62.2%)
Ear pain	72 (73.5%)
Chewing pain	70 (71.4%)
Headache	60 (59.2%)
Other pain	49 (50.0%)

\*Multiple responses possible.

## Results

### Characteristics of the Sample

One hundred and two patients, 81 women and 21 men, were included in the study. The mean age was 44.3 years (44.5 years females and 43.6 years males) and the age range 17 to 76 years. Seventy-four patients (72%) completed the PRISM task. There was no significant difference between the sample and the drop-outs for age, or for other available data in the scales analyzed below.

Complexity of orofacial pain was assessed by questions about pain location (toothache, facial pain, earache, headache, pain in other locations) and chewing as a triggering factor. Patients could indicate multiple responses. Most patients located their pain in more than one region, with the region of the ear (n = 72) being the single most frequent location selected. Seventy individuals indicated pain provocation by chewing. Most relevant characteristics are summarized in Table 1.

### Scales (PRISM, GCPS, HADS, ISI)

In the PRISM task, the SPS values ranged from 0 cm to 7.5 cm (mean  $\pm$  SD = 3.1 cm  $\pm$  2.1 cm). The distribution of SPS ratings approximated a normal distribution (Kolmogorov-Smirnov test,  $Z = 1.09$ ,  $P = .19$ ). Nineteen (25.7%) of the 74 patients who completed the PRISM task were categorized in the group PRISM-inself indicating a high burden of suffering.

Sixty-nine patients completed the GCPS questionnaire. The most frequent category was Grade 2 (53.6%) compared to Grade 3 (29%) and Grade 1 (17.4%). The intensity of pain (GCPS-PI) ranged from 0 to 9 (mean  $5.6 \pm 2.08$ ), and the mean disability (GCPS-DS) was  $3.6 (\pm 2.78, \text{range } 0 \text{ to } 10)$ . Sixty-eight patients completed both PRISM and GCPS.

The HADS-A questionnaire was completed by 91 patients. The mean score was  $6.8 (\pm 3.77, \text{range } 0 \text{ to } 16)$ . Possible anxiety disorder (HADS-A 8 to 10) was found in 30 (33%) patients and probable anxiety (HADS-A > 10) in 17 (18.7%) patients. Seventy-two patients completed both HADS-A questionnaire and the PRISM task.

Eighty-nine patients completed the HADS-D questionnaire. The mean score was  $5.2 (\pm 4.90, \text{range } 0 \text{ to } 21)$ . Possible depression (HADS-D 8 to 10) was found in 15 (16.9%) patients, and probable depression (HADS-D > 10) in 14 (15.7%) patients. Seventy patients completed both the HADS-D questionnaire and PRISM task.

The ISI was completed by 93 patients. The mean score was  $8.4 \pm 6.3$ , (range 0 to 26) among which 40 individuals (43%) had a score above 8, suggesting the presence of insomnia in these cases. Seventy-three subjects completed the ISI as well as the PRISM task.

### Correlation Between the Results of PRISM and GCPS, HADS, and ISI

PRISM strongly correlated positively with both the GCPS subscales and the ISI. There were no significant correlations with HADS-A and HADS-D (Table 2).

### Comparison Between PRISM-inself and PRISM-outself

Patients rating the pain within the “Self” circle (PRISM-inself patients) scored significantly higher on all subscales of the GCPS compared with those rating the pain outside the “Self” circle (PRISM-outself patients). A similar finding was observed for the severity of insomnia (see Table 3). PRISM-inself patients were having more severe insomnia. For HADS, PRISM-inself patients and PRISM-outself patients did not score significantly different (Table 3).

When categorizing participants based on pain duration into an acute (less than 6 months) and chronic pain group, an almost equal distribution was found between PRISM-inself and PRISM-outself ratings (Fisher’s exact test,  $P = .76$ ).

**Table 2 Correlations Between the Relevant Parameters\***

Variables	GCPS-DS	GCPS-PI	HADS-A	HADS-D	ISI
<b>PRISM</b>					
Correlation	-0.60	-0.55	-0.21	-0.21	-0.41
Significance (2-tailed)	.000	.000	.077	.078	.000
n	67	68	72	70	73
<b>GCPS-DS</b>					
Correlation		0.70	0.21	0.28	0.35
Significance (2-tailed)		.000	.091	.027	.004
n		67	65	63	66
<b>GCPS-PI</b>					
Correlation			0.23	0.29	0.21
Significance (2-tailed)			.060	.018	.085
n			66	64	67
<b>HADS-A</b>					
Correlation				0.65	0.46
Significance (2-tailed)				.000	.000
n				70	71
<b>HADS-D</b>					
Correlation					0.56
Significance (2-tailed)					.000
n					70

\*Pearson's correlations

Namely, 29.4% (five out of 17) of participants with pain for less than 6 months belonged to the PRISM-inself group, whereas in the chronic pain group, a PRISM-inself rating was given by 25.9% (14 out of 54).

**Discussion**

When managing orofacial pain patients in daily clinical practice, it is difficult to assess the impact of pain or perceived suffering as these are highly subjective and often not articulated. Aiming to optimally understand the subjective complaints of their pain patients, clinicians attempt to obtain information by comprehensive verbal descriptions or by means of a questionnaire. Compared to verbal descriptions, graphic tools such as pain drawings are often more simply and efficiently applied to explain pain experiences and therefore are widely established in medical practice and research.

The present study tested for the first time PRISM,<sup>13-15</sup> a new graphic tool designed and developed for quickly measuring subjectively perceived burden of illness-related suffering in a comprehensive orofacial pain questionnaire. Its results were compared with standard questionnaire-based assessment scales and specifically

**Table 3 Comparison Between PRISM-outself and PRISM-inself for Relevant Parameters (GCPS, HADS, and ISI)**

Variables/ PRISM groups	No.	Mean	SD	t	df	P
<b>GCPS-DS</b>						
Outself	49	3.05	2.63	-3.344	65	.001
Inself	18	5.39	2.24			
<b>GCPS-PI</b>						
Outself	50	5.22	2.04	-3.106	66	.003
Inself	18	6.83	1.36			
<b>HADS-A</b>						
Outself	54	6.31	3.46	-1.424	70	.159
Inself	18	7.72	4.13			
<b>HADS-D</b>						
Outself	53	4.58	3.97	-0.888	20.020(a)	.385(a)
Inself	17	6.06	6.47			
<b>ISI</b>						
Outself	54	7.41	6.05	-3.130	71	.003
Inself	19	12.53	6.35			

(a) Equal variances not assumed.

screened for complex pain patients with a high burden of suffering. The response rate for PRISM (72%) was comparable to the response rate for the pain-specific questionnaire GCPS (68%).

Although to date there is no general consensus regarding the characteristics of suffering and its burden of the individual, some authors require the loss of autonomy and a perception of threat to the self to create suffering. It has been demonstrated in previous studies that a low SPS correlates with these parameters.<sup>13–17</sup> The present study indicates that PRISM can assess the amount of suffering in orofacial pain patients. The most meaningful result in support of this statement was the strong correlation of PRISM with all GCPS subscales as well as with the results from the ISI. Contrary to the results of earlier studies,<sup>13–17</sup> the present study did not detect a strong correlation between the HADS subscales (HADS-A and HADS-D) and the PRISM distance SPS in this study. One reason for this rather surprising result might be that the HADS-D scores especially were low so that a floor effect may have occurred. Also in this study a low SPS correlated with higher scores in the GCPS subscales and the ISI. Pain can negatively influence the quantity and quality of sleep.<sup>25</sup> This was particularly apparent in patients classified as having a high burden of suffering (PRISM-inself patients), who have significantly higher scores on both the GCPS and ISI.

Of the 74 patients completing the PRISM task, 19 (25.7%) had placed the pain representing mark within the “Self” circle. It could be demonstrated that there was a marked difference in meaning between placing the cross in the “Self” circle compared to placing the cross remote from the “Self” circle. The PRISM-inself patients had significantly higher scores on pain (measured by GCPS) and sleep disorder (measured by ISI). This suggests that patients with a cross in the “Self” circle in the PRISM task could benefit from a more interdisciplinary treatment, including assessment by trained psychotherapists and/or psychiatrists.<sup>9</sup>

## Conclusion

PRISM was successfully applied for the first time in a sample of orofacial pain patients. By assessing simply and very quickly the subjective burden of suffering, clinicians may obtain relevant information about pain-related suffering in a simple and timesaving way. Future research should expand this pilot project and analyze if PRISM may be useful for stratifying orofacial pain patients in need of conventional primary care and multidisciplinary care, respectively.

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