

REVIEW

THE VOICE OF THE PATIENT IN OROFACIAL PAIN MANAGEMENT

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ABSTRACT

As pain cannot be measured objectively, the use of patient reported outcomes (PROs), and specifically dental PROs (dPROs), is essential for adequate assessment and management of the patient with orofacial pain. For orofacial pain conditions, some of the suitable PROs are specific to dentistry and hence can be labelled dPROs, whereas others are not. There is also a need to understand which outcomes and domains are most relevant to the patient with pain complaints within the context of the biopsychosocial model. Acute pain in the orofacial area is most often related to toothache, whereas the most common chronic orofacial pain are temporomandibular disorders. Other chronic pains in the orofacial area include neuropathic pain and unknown or idiopathic pain. PROs have been fundamental in the development of both screening procedures and diagnostic criteria in temporomandibular disorders. PROs are now often a prerequisite for the most common temporomandibular disorder pain diagnoses. Furthermore, PROs form the basis for decision-making with regard to treatment, prognostics, and referrals. Future areas of development include the standardized use of PROs in the screening and diagnostics of the less common orofacial pain conditions, together with development of core outcomes sets and standardized protocols for the use of PROs in evaluation of treatment including efficacy, compliance, adherence, and side-effects.

THE NECESSITY OF USING PATIENT-REPORTED OUTCOMES IN OROFACIAL PAIN MANAGEMENT

Pain is a deeply personal, subjective experience with a multitude of aspects that can negatively affect the individual.¹ In this context, the use of patient-reported outcomes (PROs) in clinical practice is not so much an additional tool for assessing our patients, but rather an essential prerequisite for adequate management. PROs are defined by the National Quality Forum as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."²

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Dental PROs (dPROs) have been introduced and recommended in dentistry in general,³⁻⁶ and compared to many other conditions managed in dentistry, it is extremely challenging to measure the presence of pain objectively. This means that in the area of orofacial pain management, despite much ongoing research, no universal biomarker exists and the use of PROs is instead the natural starting point for patient assessment. However, merely having outcomes reported by the patient is not sufficient – we also need to know which outcomes and domains are relevant to the patient with pain complaints. The development and use of patient reported outcome measures (PROMs)⁷ can help us capture what is important to the patient across the different domains that can be affected by pain.⁸

For the clinician, PROs/PROMs can provide crucial guidance for decision-making in a variety of areas in the assessment, prevention, and management of the orofacial pain complaints. This may also include screening and diagnostic procedures, determining treatment need and need for referral, making choices on treatment modalities and evaluating side-effects. This is especially important for the clinician's choice between treatment that is active, such as, jaw exercises, and passive, for example, pharmacological treatment, as the ability of the patient to adhere to active treatment modalities may be severely compromised by psychosocial factors.⁹ Such factors will also affect patient compliance and adherence to treatment, and thereby also the overall prognosis.¹⁰

The aim of this paper is to provide an overview of the use of PROs in the management of orofacial pain conditions. Pain and specifically orofacial pain, in the context of the biopsychosocial model, is discussed in relation to what is relevant to the patient, and how we can ensure that the voice of the patient is heard in order to optimize both treatment procedures and adherence to treatment.

THE BROADER PERSPECTIVE OF PAIN

Acute pain is typically related to a stimulus such as trauma, dental treatment or surgery, whereas many chronic pain conditions do not need such a stimulus and thus can be considered diseases in their own right; “chronic primary pain”.¹¹ Chronic pain is defined as pain that persists for more than 3 months or beyond the normal tissue healing¹¹ and can be related to peripheral and central sensitization together with a range of factors included in the biopsychosocial model. This model was introduced in the late 70s and describes that health conditions are related not only to biological, but also to psychological and social factors.¹² The model is especially relevant in the case of chronic pain and has led to the development of a more holistic approach in the assessment, prevention, and management of pain conditions. It is therefore advocated that psychosocial screening is carried out as part

of a more comprehensive assessment in health disciplines.¹³ This typically includes a range of PROs to cover domains of psychosocial, emotional, and physical function, all with specific aspects of importance with regard to the patient with orofacial pain.

THE PATIENT WITH OROFACIAL PAIN

While many patients visit their dentist for regular check-ups, pain is the most common reason worldwide for emergency dental visits.¹⁴ When patients seek dental care for acute pain, the most common diagnosis is odontogenic pain, viz., toothache.¹⁵ Thus, the patient in the dental chair with acute pain often presents with a problem with a specific organic cause.

Persistent orofacial pain is also a main reason for seeking dental treatment and the most common are temporomandibular disorders (TMDs); a collection of disorders that include pain and dysfunction in the jaw muscles, temporomandibular joint, and associated structures.¹⁶ TMDs affect about 10% of the adult population.¹⁷⁻¹⁹ Patients with TMD typically report pain in the orofacial area that is affected by jaw function, such as eating and chewing, together with psychosocial impact.^{16,20,21} In addition to TMD, which is considered to be mainly a musculoskeletal disorder, there is also a range of idiopathic and neuropathic painful conditions that can affect the orofacial region.²²

Collectively, such idiopathic and neuropathic disorders related to chronic orofacial pain are rare but with significant impact on the affected individual. Among these disorders are burning mouth syndrome (BMS), characterized by a burning sensation in an otherwise clinically healthy mucosa²³ and trigeminal neuralgia, a debilitating neuropathic disorder characterized by severe episodic pain.²⁴ Another relatively rare complex chronic orofacial pain condition, Persistent Idiopathic Dento-Alveolar Pain disorder (PIDAP), is characterized by persistent pain in the dento-alveolar region not caused by another disease or disorder.²⁵ Although the spectrum of persistent orofacial pain conditions and their origins provide a challenge for clinicians with regard to diagnostics and management, the task can be facilitated by the understanding, further development, and evaluation of PROs /PROMs.

PROs can be generic, disease specific (eg, chronic primary pain), or condition specific (eg, TMD). One advantage with generic PROs is that they allow comparisons across different diseases and conditions. For the generic PROM “quality of life,” the MOM-project (Mapping Oral disease impact with a common Metric)^{26,27} evaluated quality of life with the most widely used instrument, the Oral Health Impact profile (OHIP), across different dental conditions with orofacial pain as 1 of the 4 included domains.²⁸⁻³¹ A moderate impact on quality of life was found for the different included orofa-

cial pain conditions, viz., odontogenic pain, TMD, BMS, and pain after third molar extractions.³¹ This finding is in agreement with previous studies that evaluated a range of orofacial pain conditions and found a moderate impact in both acute and chronic orofacial pain.^{32,33} Disease-specific PROs are valuable as they can include PROMs in target areas that are specifically affected by a group of conditions, as in a group of orofacial pain disorders. Examples of disease specific PRO-based instruments for this purpose are the Craniofacial pain and disability inventory³⁴ and the Manchester orofacial pain disability scale.³⁵ Condition-specific PROMs include a TMD-specific version of the OHIP³⁶ for assessment of quality of life and the Jaw Function Limitation Scale for assessment of physical functioning.³⁷

Qualitative research methods have brought a new dimension to the area of pain research that can provide a valuable complement to the traditional quantitative research field.³⁸⁻⁴² By exploring patients' experiences and views on the impact of pain on daily living and quality of life, we can gain a deeper understanding of which outcomes and domains are important to the patient. Focus groups and different forms of interviews can provide valuable insight into patient perspectives both on items (questions) for new PROs and on how PROs, their items or domains, are perceived and interpreted by the individual patient as opposed to the clinician. This is an opportunity not to be missed and especially relevant for the management of orofacial pain.

THE USE OF PROS IN SCREENING FOR OROFACIAL PAIN CONDITIONS

Although PROs were originally developed for evaluating treatment outcome, they can also be considered for screening purposes, and have been discussed in relation to routine symptom screening.⁴³ Screening procedures can serve the purpose of identifying patients in need of a more comprehensive assessment and extended examination for a specific disease or condition. Specifically, with regard to orofacial pain, screening instruments based on PROs have been developed, validated, and implemented in different contexts. In large parts of Sweden, 3 PRO-based screening questions (3Q/TMD) were introduced in the public dental health system from 2000. These screening questions were validated in adolescents in relation to the Research Diagnostic Criteria for TMD (RDC/TMD)⁴⁴ and in adults in relation to the Diagnostic Criteria for TMD (DC/TMD).¹⁹ Furthermore, the 3Q/TMD were recently recommended for use in both children and adolescents when screening for TMD.⁴⁵ Although the screening questions were introduced in the public dental health system with the aim to identify patients in need of a more detailed assessment in the clinical setting, their widespread use has also allowed collection of large scale real-world data for epidemiological purposes.^{17,19,46,47} In addition to the 3Q/TMD, in 2011, 2 PRO-based 5-item

screening tools, developed specifically for TMD, were published.^{48,49} Both were validated in adults in relation to the RDC/TMD and 1 of them, the TMD pain screener, was incorporated in the diagnostic procedure for TMD.⁴⁸

THE USE OF PROS IN THE DIAGNOSIS OF OROFACIAL PAIN CONDITIONS

PRO's have been instrumental in the development of diagnostic criteria for the most common chronic orofacial pain conditions, TMDs. RDC/TMD were introduced in 1992 and incorporated a dual-axis system: Axis I for a physical diagnosis and Axis II for psychosocial assessment.¹⁶ The incorporation of the biopsychosocial model in the criteria provided a shift from clinician-based outcomes to PROs that was further emphasized in the revised criteria, the DC/TMD.⁵⁰ The DC/TMD is intended for use both in research and in the clinic by general dentists as well as specialists, and can provide crucial guidance for decision-making, especially in the clinical setting. An expanded version of the DC/TMD has also been introduced to cover less common disorders.⁵¹

For a physical diagnosis according to Axis I of the DC/TMD, specific items from the PROM Symptom Questionnaire together with a location-specific pain report is required from the patient, followed by confirmation of "familiar pain" provoked during the clinical examination procedure. For the psychosocial assessment, that is, Axis II, different levels of screening are recommended, both specifically for TMD in the DC/TMD and broadly for the recently developed International Classification of Orofacial Pain (ICOP).²² The recommended standard psychosocial screening is based on PROMs to assess pain intensity and related disability, functional limitations, psychological distress, oral parafunctional behaviours, and pain location (Table 1). Collectively, these PROs will guide the clinician in determining treatment need, treatment modalities, prognosis for treatment outcome, as well as the possible need for referral.

With regard to other chronic orofacial pain conditions, disease-specific diagnostic criteria have now been developed also for BMS with similar structure and focus on PROs as in the DC/TMD.⁵² Furthermore, diagnostic criteria for trigeminal neuralgia are under development.

The development and revisions of the diagnostic criteria and PROs described above have in large parts been developed in a series of workshops, consensus meetings, and publications driven by the International Network for Orofacial Pain and Related Disorders Methodology (INFORM; <http://www.iadr.org/>; previously the International RDC/TMD Consortium Network of the International Association for Dental Research). Together with several other groups and organizations, INFORM also participated in the development of the new comprehensive ICOP that was published in 2020 with

Table 1. Patient reported outcomes (PROs) and PRO measures (PROMs) recommended in the standard psychosocial assessment in the Diagnostic Criteria for Temporomandibular Disorders (DC/TMD) and the International Classification of Orofacial Pain (ICOP).

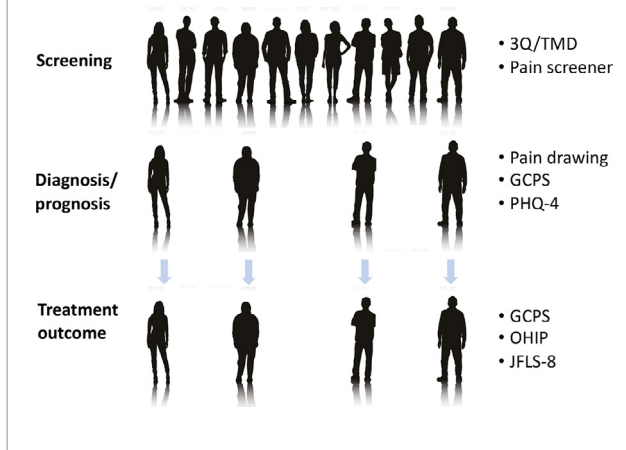
PROs	PROMs	Number of items	Type of PROM
Pain intensity and related disability	Graded Chronic Pain Scale	8	Disease specific
	Graded Chronic Pain Scale-Revised	5	Disease specific
Functional limitations	Jaw Function Limitation Scale - 8	8	Disease specific
Psychological distress	Physical Health Questionnaire - 4	4	Generic
Oral behaviors	Oral Behavior Checklist	20	Disease specific
Pain locations	Pain drawing	1	Generic/Disease specific

the aim to facilitate understanding and communication between different health care providers.²²

THE NEXT STEP- FUTURE AREAS OF DEVELOPMENT

The impact of pain, especially when chronic, can involve many different areas of life for the affected individual. The Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) recommended core outcome domains that should be used in clinical trials evaluating treatments for chronic pain in general.⁵³ In addition to pain, the other 5 core domains identified were physical functioning, emotional functioning, satisfaction with treatment, adverse effects, and adherence to treatment. These generic IMMPACT recommendations have been followed by development of disease-specific recommendations for BMS,⁵⁴ evaluation of the use of IMMPACT outcomes in trigeminal neuralgia,⁵⁵ and reflections on the relationship between these criteria and the DC/TMD.⁵⁶ This mapping of domains considered important in clinical trials, was followed by recommendations for the use of PROs, where the need for further development was recognized.⁵⁷ The patient perspective was evaluated in a survey that identified 19 different aspects of daily life deemed important by the patients. It was concluded that especially life enjoyment, emotional well-being, fatigue, weakness, and sleep-related problems were significant for the patient.⁵⁸ The discrepancy between the use of these PROs, deemed important by the patients, and the use of clinician-reported outcomes for patients with chronic pain was evaluated in a mapping study of 60 trials. It was found that of the identified 19 different aspects, only 2 (viz. emotional wellbeing and physical activities) were sufficiently evaluated.⁵⁸

Figure 1. Examples of PROMs that can be considered for the orofacial pain patient at different stages of healthcare; screening, diagnosis together with psychosocial assessment for prognosis, and evaluation of treatment outcome. GCPS, Graded Chronic Pain Scale; JFLS-8, Jaw Function Limitation Scale-8; OHIP, Oral Health Impact Profile; PHQ-4, Physical Health Questionnaire-4; 3Q/TMD, 3 questions Temporomandibular Disorders.



Based on the above, we should aim to develop standardized PROs and core outcome sets also for the evaluation of treatment outcomes for patients with orofacial pain (Figure 1). This is in line with the COMET initiative, with the aim to develop and standardize core outcomes (<https://www.comet-initiative.org>) in clinical trials generally and specifically targeting different areas of dentistry.⁵⁹ As described earlier, this can include both generic PROs, and PROs targeting a specific disease or condition. For the patient with

orofacial pain, quality of life is significantly affected in both acute and chronic pain conditions, and subsequently this is 1 domain that can be recommended to be assessed also when evaluating treatment outcomes. Assessment of health-related quality of life in orofacial pain patients with the generic OHIP was described earlier, and has been reported in a range of studies with regard to treatment outcomes in both acute and chronic orofacial pain conditions.³¹ The general use of PROMs in patients with BMS were reported in a systematic review to include symptom severity and symptomatic relief, quality of life, and depression/anxiety.⁶⁰ A follow-up study after arthroscopy found that the PRO “functional jaw limitations” correlated with the clinical findings.⁶¹ More condition-specific PROs may have superior responsiveness, that is ability to measure change over time, and therefore be more appropriate in evaluation of treatment.

RECOMMENDATIONS

In the management of orofacial pain conditions, the use of PROs is recommended in the DC/TMD and ICOP as part of diagnostics and psychosocial assessment. For psychosocial assessment, we recommend that the general dental practitioner assesses psychological distress (PHQ-4) as this is of special relevance. For the monitoring of patient progress, pain intensity, and related disability a simplified short instrument (Graded Chronic Pain Scale-Revised) is now available.⁶² For the evaluation of treatment outcome, further work is needed to standardize the use of generic PROs and disease-specific core dPROs for the orofacial pain patient. New core outcome sets of PROs should cover the 6 domains recommended by IMMPACT, be responsive to change and have other appropriate psychometric properties. For these purposes, the generic PRO “quality of life” (OHIP) together with disease-specific physical functioning (Jaw Function Limitation Scale) and pain intensity and related disability (Graded Chronic Pain Scale) may be suitable as general recommendations. The domains that can be considered more related to specific treatment modalities, viz., satisfaction with treatment, adverse effects, and adherence to treatment, may require more specific considerations depending on the type of treatment that is being evaluated.

CONCLUSION

Taken together, the development of PROs and understanding of what matters to the patient has provided an opportunity for both clinicians and researchers to improve the management of orofacial pain conditions, for the benefit of both the individual patient and ultimately for the society at large.

CREDIT AUTHORSHIP CONTRIBUTION STATEMENT

Birgitta Häggman-Henrikson: Conceptualization Methodology Roles/Writing – original draft review & editing. **Frank**

Lobbezoo: Conceptualization Methodology Roles/Writing –review & editing. **Justin Durham:** Conceptualization Methodology Roles/Writing –review & editing. **Christopher Peck:** Conceptualization Methodology Roles/Writing –review & editing. **Thomas List:** Conceptualization Methodology Roles/Writing –review & editing.

ABBREVIATIONS

BMS, Burning Mouth Syndrome; DC/TMD, Diagnostic Criteria for Temporomandibular Disorders; dPRO, dental Patient Reported Outcomes; PRO, Patient Reported Outcomes; PROM, Patient Reported Outcome Measures; RDC/TMD, Research Diagnostic Criteria for Temporomandibular Disorders; TMD, Temporomandibular Disorders

SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jebdp.2021.101648.

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