

The Meaning of Words Related to Orofacial Pain and Headache Conditions: The Need for a Single and Unified Classification Scheme in a People-Centered Language

There have been recent initiatives to improve the classification schemes for orofacial pain and headache conditions.¹⁻³ Classification schemes and glossaries related to them are dynamic in the sense that they are works in progress that require periodic updating to take account of scientific and clinical advances as well as societal changes bearing on them, such as the recent move toward more “people-centered language.”¹⁴ While these three recent schemes represent landmark steps in the orofacial pain and headache field, there are many common elements among them, although not all have included a detailed glossary and definition of terms. This has led us to suggest that two further steps are needed. These three classification schemes overlap in many respects, and there seems merit in consolidating them into one scheme. Although a reclassification of each condition is not needed, the first step that we suggest is to unify these schemes so that the orofacial pain and headache field has one classification scheme that is widely accepted and used by clinicians and researchers in the field. Furthermore, we also suggest a second step, which is for this scheme to incorporate a more detailed glossary of terms than presently exists in order to ensure a common language is put in place for the terminology and words used by clinicians and researchers in the field for their communications with patients and with each other. These two steps would go a long way in avoiding what Svensson et al refer to as a “Babylonian confusion.”¹⁵ We outline below three points that underpin the reasoning for our suggestions.

The first point is the persistent use by many clinicians and authors of terminology that has generally been supplanted by more recent evidence-based terminology. For example, take the term “Costen’s Syndrome,” a condition suggested in 1934 in relation to what is now known in current classifications as a temporomandibular disorder that may have overlapping otalgic symptoms.⁶⁻¹¹ The continued widespread use of this term in the medical and dental literature is revealed by a rapid general web search using the term; such a search also results in a link to clinical advertising for treatment of orofacial, ear, and neck conditions in relation to Costen’s Syndrome. There is even an insurance reimbursement code that is still in use for the term Costen’s Syndrome. Why does such a clinical descriptor persist in the literature in the face of evidence-based studies documenting its out-of-date misrepresentation of the condition? Perhaps its persistence reflects in part the

deep belief of some clinicians and authors in the clinical features and causes noted in the original descriptions of Costen’s Syndrome.¹¹ The attachment to this term by some clinicians and authors could also reflect a misunderstanding of evidence-based knowledge and its importance in selecting the best treatment for a given individual with orofacial pain and headache. Whatever the case, continued use of this term points to the need to innovate our strategies to improve knowledge translation and dissemination of scientific advances and the evidence bearing on orofacial pain and headache and their classification. It also underscores the need for a single, unified, and widely accepted classification scheme with a detailed glossary that includes terms that are noted as being outdated and that have been replaced with evidence-based terminology.

The second point relates to the need for clinicians and others to recognize the meaning and impact of words they use when communicating with patients. We are in what might be thought of as a major mutation period of what is commonly called “political correctness” as increased societal attention is paid to the need for due recognition of gender, race, and age differences in society, and for avoidance of gender, racial, and age discrimination. As clinicians and researchers, we accordingly have to ensure that we not only avoid such discrimination in our clinical and research interactions but also avoid pejorative language. In the field of medical publication, many changes have been adopted in relation to the status given to a patient with an illness. For example, the journal *Sleep* now has a major requirement for submission that “people-centered language” must be used in the manuscript.⁴ Examples of what this would mean for the field of orofacial pain and headache are the use of person (or individual) with orofacial pain instead of orofacial pain patient; weight problem instead of obese or overweight; person experiencing pain instead of person suffering from pain; economic impact of pain instead of economic burden of pain; self-reports instead of subjective reports; participants in a clinical trial instead of subjects in a clinical trial; and adherence to treatment instead of compliance with treatment. The reasoning behind these changes is exemplified in this last example, as the term “noncompliance” can be perceived as stubbornness toward adopting clinical guidance for a change in lifestyle or medication use. These examples underscore the need for clinicians to build a therapeutic alliance in the form of a clear partnership with the person for whom they are called upon to

provide health care.¹² Being more sensitive to societal changes and the need to use clinical correctness language are in line with the concept of the “patient partner” in reaching a decision on the choice of treatment.¹³

The third point relates to the use of terms or words that may be synonymous, but depending on the context of their usage, may have different meanings. Thus, how they are used could create confusion or be misinterpreted by the person hearing or reading the words. Clinicians, academicians, and politicians can be artisans in generating such confusion. The current COVID-19 pandemic is an example, since it has drawn attention to the importance of words and their usage. Health professionals and government spokespersons have often presented confusing or inconsistent messaging about COVID-19 and had their statements misunderstood by the public, to the detriment of well-intentioned public health measures to control the pandemic. Furthermore, the words used by a person with orofacial pain to describe their pain may differ from the ones used by the clinician making a diagnosis or the ones used by an investigator carrying out an experimental protocol in healthy participants. For example, “fatigue” and “tiredness” may be synonymous, but do they have the same meaning for a person with muscle pain as for a clinician or researcher? On one hand, muscle fatigue during a certain motor task can be objectively quantified as a physiologic parameter of muscle motor function by a researcher using electromyographic measures. On the other hand, muscle fatigue and tiredness are subjective terms that can instead be self-reported by a person; for example, after an experimental clenching task or upon waking up in the morning. In the latter instance, the term is understood by most clinicians as a term that is a diagnostic indicator of sleep bruxism, sleep apnea, or recent traumatic brain injury. Muscle “tenderness” is another example of a term referring to a feature of muscle function that can be quantified (in this case with a pressure-pain device) as a physiologic parameter of muscle sensory function but also can be self-reported by a person under an experimental protocol or by the person if they have a musculoskeletal pain. The person may use “tenderness” to grade and report their perceived muscle pain, which the clinician or researcher may interpret as muscle pain, myalgia, muscle soreness, or muscle tenderness. These words are probably not all the same, since each is reported in a different context under different situations. Moreover, each can be associated with more than one diagnosis and have different risk factors and mechanisms; the differential diagnosis can be even more challenging if it is reported in the presence of comorbidities.

The three points outlined above underscore the importance of having a single, unified classification scheme that also extends the current glossary of orofacial pain and headache terminology using people-

centered language to reduce the “Babylonian confusion.”¹⁵ Ideally, such a glossary would be made readily available not only by pain societies but also by publishers and editors of journals, books, and guidelines in their instructions to authors so that pain-related publications use a common terminology and language. Such an approach would be a natural extension of the current classification schemes and also help facilitate the translation of evidence-based knowledge and a common people-centered language to clinical practice and clinical research. Importantly, it would contribute to reducing confusion in the use and understanding of clinical terminology in the field of orofacial pain and headache and thereby help improve the relationship between the person with pain and the clinician through the use of well-defined words that have the same meaning to both.

Gilles Lavigne, Associate Editor
Barry Sessle, past Editor-in-Chief (1997–2018)

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