Let’s Adopt ICOP: Speaking the Same Language

The language of diagnostic medicine, or how we communicate conditions and disorders to our patients, colleagues, and institutions, is possibly the only true international language. The essential components are the terms we assign to a cluster of signs and symptoms—that is, the diagnosis, which we believe to reflect a disorder or disease. The creation of the International Classification of Orofacial Pain (ICOP) is an attempt to establish “our” common language.

Accurate and effective communication relies on the diagnostic terminology found in disease classifications, which are the dictionaries of medical diagnoses. We make a big deal of classifications—and rightly so, for they are essential to many aspects of health care, from establishing international policies to prescribing the most adequate treatment for our patients. For me, the latter is the most important. Internationally accepted classifications improve treatment outcomes, and the more accurate they are, the better our patients will feel.1

A classification must define its limits and what it will include. For ICOP, this would be orofacial pain (OFP), including painful temporomandibular disorders (TMDs) and some headaches. A classification is based on a plan or “schema” depending on its purpose and on the logic of its designer (committee). In the “perfect” classification, the groups and the level of detail may be versatile enough to cover a number of purposes. The International Classification of Headache Disorders’ (ICHD) hierarchical system allows increasingly detailed levels of diagnosis, with each level suiting a specific purpose, and has been used to help create the ICOP.

Philosophically, different classifications may adopt different groupings. “Lumpers” will tend to prefer classifications with major definitions that include larger patient populations, while “splitters” tend to subclassify. At their extremes, “lumpers” often make the mistake of combining unrelated disorders, and “splitters” may conclude that there are no diseases, only patients! We need both approaches, of course.

Let’s not be fooled: Until we truly understand the etiology of a complaint or disorder, medical terminology is by necessity imprecise. In other words, diagnosis should not be confused with disease. We often make diagnoses of unknown underlying processes (this is common in every medical field), so almost by definition, then, classifications are a work in progress, constantly changing as we better understand diseases—for instance, take the tremendous progress made from the first headache classification to the ICHD-3 in 2019. But pain diagnosis remains clinical, relying heavily on the specific combination of history, clinical signs, and symptoms. How do we validate these diagnoses? The criteria are field tested; circular reasoning that adds to the current problems we face validating our classifications.

Ideally, ICOP would be completely based on etiologic or mechanism-based criteria, but this is complex in OFP and headaches due to multiple or unknown mechanisms. Biologic and genetic biomarkers are slowly improving our classifications in medicine, but there are few in current use for the diagnosis of primary OFP2 and headaches.3

As we elucidate the exact processes underlying these disorders, diagnosis approaches etiology and ultimately an understanding of the true disease—and, if we are lucky, specific diagnostic biomarkers. Notwithstanding these inherent limitations, current classifications have no better alternative in the foreseeable future.

Unfortunately, we still have no widely accepted classification for OFP. There are a number of relevant classifications, but they are not integrated and not in complete accord (for review, see Renton et al4). This is hindering our clinical and research efforts to better understand OFP. Without a clearly defined clinical phenotype, there can be no reliable research into etiology, genetics, and outcomes. Additionally, although the face is clearly part of the head, a distinct diagnostic classification for OFP may help avoid cases of misdiagnosis and resultant mis-directed treatment. The reality in clinical practice is that “headaches” often refer to “orofacial” regions and vice versa. At times, “headaches” may be located exclusively around the “orofacial” region and may cause significant diagnostic difficulties. OFP refers to the head presenting a complex clinical phenotype. In particular, dental pain due to local dental pathology is often blamed for primary orofacial and head pains. With no comprehensive, internationally accepted classification that deals with OFP, we remain devoid of a gold standard.

These were some of the factors underlying the necessity for a system such as the ICOP. I admit that for many years I have envied the ICHD and dreamed a similar system could be created for OFP. The concept of an ICOP took root, but it was clear that success depended on international collaboration and individual leaders investing their time and effort. During my time as chair of the Orofacial & Head Pain Special Interest Group (OF&HP-SIG) in the International Association for the Study of Pain, we initiated a close and strategic collaboration with the International Network for Orofacial Pain and Related Disorders Methodology (previously the International RDC/TMD Consortium Network), the International Headache Society, and the American Academy of Orofacial Pain and its sister academies. The road to ICOP began in 2016, when we first met at the World Congress of the International Association for the Study of Pain (IASP) in Yokohama, Japan. During the 1-day meeting facilitated by the Asian Academy of Craniomandibular Disorders, we discussed the structure and established working groups. A follow-up meeting was held at the Rutgers School of Dental Medicine,

doi: 10.11607/ofph.2019.3.e

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Rutgers, New Jersey, USA, in 2017, and finally a summary meeting at the IASP World Congress in Boston, Massachusetts, USA, in September 2018. The result is a classification, backed in many areas by strong evidence and in others by expert opinion, that will encourage and guide OFP research. The members of the classification committee working groups went beyond expectations and have produced a masterpiece that we will all be proud of. There were many who helped carry this project through to completion: In particular, though, Dr Peter Svensson, Dr Arne May, and I provided all the leadership and hours of work we could muster, and Dr Lene-Baadal Hansen, the OFHP-SIG treasurer, worked tirelessly to facilitate and coordinate.

ICOP is pragmatic and adopts the DC/TMD criteria for arthralgias and myalgias, recommending the use of its Axis II assessment tools. It accepts and integrates the ICHD-3 classification and is also aligned with the ICD-11/IASP criteria for OFP and headaches. Its structure is hierarchical and mimics that of the ICHD-3 for consistency. This is a tool that will enhance research and the clinical management of OFP and that aims to bring professionals working on head, orofacial, eye, nose, sinus, and neck pain closer and to encourage active collaboration. Ultimately, we must aim to improve the care of our patients in pain. ICOP is nearly here, undergoing final editing before publication. We chose the journal *Cephalalgia* carefully. This journal is the home of ICHD and will provide wide exposure to ICOP. As a believer that head and face pain belong together, we must walk together.

Is the ICOP perfect? No, of course not. As I write this editorial, I am certain that new research is being performed that will alter our understanding of the entities described and therefore the criteria for diagnosis. As stated, classifications from their inception are destined to be modified, and we must not fear this, for research leading to change and progress is always a good thing.

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References