May 31, 2020

Dr. Sherin Tooks
Director, Commission on Dental Accreditation
211 East Chicago Avenue
Chicago, IL 60611

RE: Proposal Revision to Standard 2-24k of the Accreditation Standards – The TMJ Association Endorses the Inclusion of TMD into the Dental Education Programs

Dear Dr. Tooks,

The TMJ Association (TMJA) is a nonprofit patient advocacy organization whose mission is to improve the quality of health care and lives of everyone affected by Temporomandibular Disorders (TMD). For over 30 years, we have advocated for the highest quality of science that would bring understanding to these disorders, as well as safe and effective treatments to help and not harm patients. In addition, we are the 911 for people whose TMD resulted from a dental procedure or TMJ treatment. We are contacted by people who think they have a TMJ issue or have been diagnosed as having TMD and find the inconsistency in information available on this condition daunting and conflicting.

State of Professional Responsibility in TMD
In 2016, the TMJA, in collaboration with the US Food and Drug Administration (FDA) and other stakeholders, developed the TMJ Patient-Led Round Table, with a broad goal of improving treatment outcomes for TMD. Several working groups (WG) were formed, and one - whose aim was to assess treatment directives, educational criteria and patient centeredness, and whether practitioners adhere to them - found that there are 24 separate organizations who claim superiority (without evidence) in their treatment methods. Further, the WG found that there are no formally developed guidelines, standards of care, nor best practices to inform dentists on evidence-based and patient-centered care, despite the routine prescribing of their procedures and treatments. In our first brochure written in 1993, in a section on treatments we stated, “You may get better, you may be unaffected, or you may get worse - without science, this is TMJ lotto.”

Because the American Academy of Orofacial Pain (AAOP) has been touted as one of the leading organizations in TMD care, we have used their website information on TMD
treatments and compared those treatments with the NAM report’s evaluation of the same treatments as an example of professional organization’s espousing treatments that have been shown to lack scientific rigor.

The graphic below is from the AAOP’s website summarizing its TMD treatment strategies.

The following assessment of these same treatments is contained in the NAM Report:

- **“Self-management, stress management and patient education** can be important components of care of temporomandibular disorders (TMDs). People with TMDs need access to self-management resources, including formal training. Research is needed to test and refine self-management interventions in order to identify which techniques are most effective, to determine which patients are most likely to see benefits, and to understand the mechanisms of self-management for TMDs.” (NAM report, 5-11)

- **“Some elements of physical therapy—including exercise and manual therapy**—have been shown to improve pain and functional outcomes for
individuals with temporomandibular disorders (TMDs). However, many of the studies are of low quality and further research is needed to support the use of these treatment modalities.” (NAM report, 5-17)

- “There are **no drugs** specifically approved by the FDA for this disorder, and the evidence for efficacy of many of the recommended treatments is weak.” (NAM report, 5-19)
- “**Intraoral splint therapy** may confer a small benefit for the management of pain in individuals with TMDs, but the evidence for this is generally poor and mixed.” (NAM report 5-16)
- “There is no universally accepted protocol for **operative management** of a TMD.” (NAM report, 5-23)
- Although **botulinum toxin Type A** is not listed in the graphic above, it is a treatment that has recently been zealously embraced as a treatment for TMD without conducting clinical trials. “Some studies have reported improvement in facial pain in some patients with TMDs from botulinum toxin Type A injection into the muscles of mastication but others have reported equivocal results; the data are limited and often of poor quality. There is concern for the health of the TMJ in humans using botulinum toxin Type A in the long term given the osteoporotic condition of the TMJ in rabbits.” (NAM report, 5-21-22)

**Conclusion 5-5** in the NAM report states, “Data are inadequate and are of poor quality for most treatments for temporomandibular disorders (TMDs). Research is needed to determine safe and effective treatments for TMDs. Systematic reviews and methodologically rigorous new studies are needed.”

The National Academy of Medicine’s (NAM) March 2020 landmark report (**Temporomandibular Disorders: Priorities for Research and Care 2020**) addressed treatment controversies stating, “This debate highlights the deep divide between different approaches to TMDs, and how the lack of clear evidence creates confusion about how to treat TMDs. At present, even the principle regarding what constitutes strong evidence remains disputed. Absence of training in research methods and statistics or in the skills needed to critically evaluate published literature pervade much of the dental field. Without such critical skills to evaluate evidence and incorporate it into the behavioral repertoire of the clinician, the deep divide between those who adhere to belief-based models versus those who work flexibly and adaptively according to current evidence will continue.” (NAM report, 5-32) **In summary, the dental profession has neglected its ethical responsibility to those who have entrusted themselves to its care.**

**The Deleterious Consequences for Patients**

The consequences of this negligence are what The TMJ Association is left to deal with. Patients tell us of bankruptcies due to exorbitant treatment costs, jobs lost because of inability to perform tasks, career dreams abandoned, family plans gone awry, divorces, lost friendships and isolation. Eating, swallowing, speaking and even breathing is comprised. Having one’s face touched in a hug or kiss is unbearable, as is seeing one’s paralyzed or distorted face in a mirror—a face that they no longer recognize. Frustrating
is the inability of their physicians to comprehend their TM Disorder. The betrayal of trust by their “specialist” when patients are harmed, abandoned for financial reasons or because treatment complications escalate, expands to include loss of trust in all health care professionals, their spirituality, the government and even themselves. The thought of a dental appointment triggers PTSD attacks. Families notify us of their loved one’s suicides. Patients describe the unbearable never-ending pain that no one seems to know how to treat (but profess they do) - and how when treaters no longer hold out hope, blame the patients, deny the problem or offer platitudes. For decades, the literature has neglected the topic of harm. In a 2015 paper by Gewandter, he states, “Proving direct harm from an intervention usually requires very large and well-designed studies—a rarity in the world of TMDs. Many treatment studies of TMDs have been generally poor with regard to adverse event collection methods and reporting.” When patients are harmed by treatments, they have little legal recourse, because without clinical practice directives, it is difficult to prove the treater did not act according to such directives. **Therefore, there is no accountability and no one is responsible for the harm.**

**A Dental Problem or a Complex Condition?**

Though research on these conditions are in its infancy and there is much more to be learned, recent research results have demonstrated that TMDs are complex medical conditions that involve multiple body systems, rather than just a localized jaw condition. The cardiovascular, neurological, immunological, digestive, respiratory, endocrine and musculoskeletal systems contribute to the onset, development and/or persistence of TMD, as well as influence treatment outcomes.

The 2020 NAM study states: “TMDs have a high comorbidity with multiple medical conditions, including other idiopathic pain conditions, systemic medical conditions that include pain as a primary symptom, and health conditions whose primary symptoms are not pain (see Box 3-2).” (NAM report, 3-19) “For example, results from the Orofacial Pain Prospective Evaluation and Risk Assessment (OPPERA) study demonstrate that individuals with a painful TMD reported more pain conditions (e.g., back pain, irritable bowel syndrome, headaches) and a
greater number of medical comorbidities, particularly neural/sensory and respiratory conditions, than did controls (Ohrbach 2011).” (NAM report, 3-17) We have also heard from an increasing number of patients whose physicians have noted the link between TM disorders and connective tissue conditions. The OPPERA study – the first, prospective longitudinal study to assess the complexity of TMD using a multisystem approach - stated, “It is a misnomer, and no longer appropriate, to regard TMD solely as a localized orofacial pain condition. For the majority of people with chronic TMD, the condition is a multisystem disorder with overlapping comorbidity.” Cumulatively, these findings call for a paradigm shift in the research, understanding and care of TMD patients toward a multidisciplinary, multisystem approach. Clearly, the explosion of this new information indicates that we must transform TMD research and patient care to align with what science dictates, necessitating the inclusion of multiple medical and allied professionals.

The American Dental Association (ADA) agreed with this conclusion, which was reflected in the presentation provided by Dr. Deepak Kadami, the ADA representative during the March 2019 NAM meeting. He stated, “We need to ensure that pre-doctoral education both in medicine and dentistry is actually optimized to teach TMJ. We need to also understand the post-doctoral programs, be they family medicine residency, internal medicine programs, general practice residency; and the whole other gamut of medical and dental specialties need to be engaged in the education of TMJ care.”

The chaos and controversy existing in this area for the past 80-plus years has had a profound effect on patients, including Adriana, who eloquently expressed this in her presentation to the NAM committee when she stated, “Our current system for treating TMD is not only broken, but it’s fragmented, and patients are falling through the cracks and are left feeling abandoned and alone. These cracks are actually more like a huge gap or a divide between the fields of dentistry and medicine, and it is in this no man’s land that TMD patients find themselves.”

What Dentists Need to Know
Since patients typically seek care from dentists for TMD, it is unethical to not provide them with evidence-based education to guide patient care. We ask that information on TMD be included in the dental school curriculum, just as we will be asking that the fundamentals of TMD are also included within the educational curricula for medical, nursing, physical therapy, and other allied health professionals.

Considering that the NAM study has revealed a comprehensive view of the state of TMD there is a limited amount of scientific information to be relayed in the educational curricula. Topics that should be included in the Dental Curricula include, but are not limited to:

- **Do no harm.** Professional school education on TMD, if limited to evidence-based information/treatments, offer very little for the dentist to administer to patients. The prime directive should be to do no harm.
• **De-implementation of TMD treatments.** Dentists should learn that the current treatments lack the necessary evidence of safety and efficacy. They should be trained in research methods, statistics, and skills needed to critically evaluate published literature.

• **Self-care.** Realize that to date, three different clusters of patients have been identified through the OPPERA study. Educate the patient on the state of science and knowledge of TMD and reassure patients that it is common for many to improve without treatment.

• **TMD is a complex set of medical conditions.** TMD involves multiple body systems and multiple comorbidities that are not addressed in dentistry. Be aware that the cardiovascular, neurological, immunological, digestive, respiratory, endocrine, and musculoskeletal systems contribute to the onset, development and/or persistence of TMD, as well as influence treatment outcomes.

• **Medical and allied health professionals.** For those patients with chronic TMD, connect with the patient’s medical and allied health professionals to develop a collaborative working relationship. Be mindful that treatments for other comorbid conditions may impact TMD symptoms (and vice versa).

• **Special care needs & basic care.** Many TMD patients find it impossible to have their general dental needs addressed due to their limited mouth opening, pain, and the extended time needed for appointments. The dental community needs to acknowledge that the oral disability and pain demand special care when receiving general dental treatment.

• **Triggering a TMD issue.** Be aware that prolonged mouth opening and over extending the mouth opening can trigger a TMJ problem during general dental care.

• **Patient-centered care.** Dentists must learn the concepts of patient-centered care – develop good communication skills, address patient’s needs effectively and strive to provide care that not only is effective but safe.

• **History of temporomandibular disorders.** Learn about the history of TMD, and treatments.

**New Treatment Model**

The NAM has discussed the harm that has been caused by the divide between medical and dental care, stating, “A challenge to the TMD field is to find innovative ways to cross the medical and dental divides in training and in practice and to find opportunities for post-graduate physicians, nurses, and other health providers to become more engaged—through fellowships, continuing education courses, integrative research, and other efforts—in TMD care and research. Given the great strides in care for knees, shoulders, and other joints of the body, the committee urges similar levels of attention to the temporomandibular joint and TMDs.” (NAM report, 6-9) It’s clear that field of TMD is in need of a major transformation and it is only fitting to begin with the education of dentists, medical professionals, and others needed in treating TMJ patients.

Patients have played and continue to play a major role in bringing attention to the need to advance the understanding of and ability to treat TMDs. (NAN report, S-3) The TMJ
Association would be happy to work with the American Dental Association in any way that will lead to improved health care and lives of TMJ patients.

Sincerely,

[Signature]

Terrie Cowley  
President & Co-Founder  
The TMJ Association  
P.O. Box 26670  
Milwaukee, WI 53226