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Temporomandibular Disorders Priorities for Research and Care

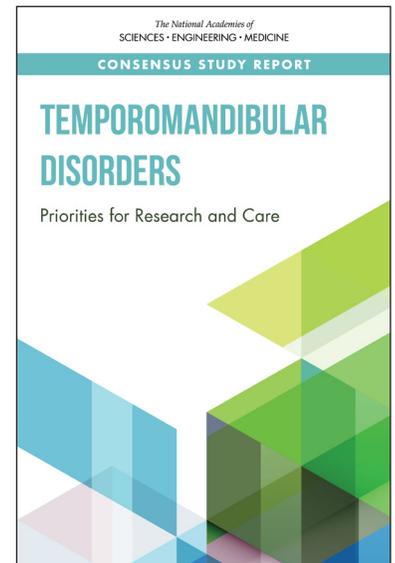
People use their jaws for many of life's most essential daily tasks, including eating, talking, kissing, and even breathing. When someone develops a disorder of the jaw, known as a temporomandibular disorder (TMD), it can have a measureable impact on that person's health and quality of life. TMDs make up a set of over 30 health disorders associated with both the temporomandibular joints and the muscles and tissues of the jaw. TMDs can be short-term or long-lasting, with symptoms ranging from the occasional click to severe chronic pain throughout the face and mouth. TMDs can occur at different stages in an individual's life with a range of manifestations, impacts on quality of life, and simultaneous health conditions. Based on one analysis of data from 2018, an estimated 4.8 percent of American adults have pain in the temporomandibular joint region that could be related to TMDs.

Action is urgently needed to improve care for individuals with TMDs. Individuals with TMD symptoms often encounter health professionals (across medicine, dentistry, and other areas) that are unfamiliar with these disorders and are not sure of the best place to refer patients for further diagnosis and treatment. In the United States, one of the major barriers to effective TMD care is the vast divide between medicine and dentistry where there are separate professional education systems, care practices, and payment mechanisms.

With support from the Office of the Director of the National Institutes of Health (NIH) and the National Institute of Dental and Craniofacial Research (NIDCR), the National Academies of Sciences, Engineering, and Medicine appointed a committee to address the current state of knowledge regarding TMD research, education and training, safety and efficacy of clinical treatments, and associated burden and costs.

PATIENT EXPERIENCES

Patients play an essential role in advocating for better understanding and treatment options for TMDs. The committee received input from over 110 individuals living with TMDs on their experience with these disorders. Individuals with TMDs experience significant day-to-day challenges, including difficulty in



eating, socializing, and talking. These challenges are often accompanied by severe ongoing pain. Many individuals with a TMD or their family members commented on:

- **Lack of coordinated care and abandonment.** Individuals reported that they were often shuffled back and forth between medical and dental practitioners with little to no attention paid to a comprehensive approach or coordinated care. Patients also reported being abandoned by their dentists and other clinicians when the treatments did not work, with no referrals or other options provided.
- **Over-treatment/harmful treatment.** Many patients reported multiple TMD-related surgeries—in some cases more than 20—often with no resolution to their pain or with worsening symptoms. Other individuals who did not receive surgical care reported being provided with a removable oral appliance, orthodontic correction of the teeth, replacement of teeth, or some combination of these treatments.
- **Impact on quality of life.** Individuals with a TMD reported profound impacts on the quality of their day-to-day lives, from struggling in pain to kiss a loved one to challenges in dining out with friends or simply eating solid foods. Many described challenges in dealing with the emotional consequences of their condition and its treatment and with the episodic or ongoing pain that they experience.
- **Expense.** Individuals and their families noted the significant financial burden of seeking and receiving care for a TMD. Some people said that they had received limited insurance coverage, but most patients paid for at least some coverage out-of-pocket, costing up to tens of thousands of dollars per patient.
- **Difficulty identifying qualified health care professionals.** Individuals with a TMD and their families often expressed frustration at not knowing where to turn for quality care. Misleading advertising practices—in which clinicians claim to be experts but do not have the proper experience or evidence-based practices—further complicate access to quality care.
- **Overlapping conditions.** Many individuals with a TMD noted challenges with other conditions resulting from or occurring along with their TMD disorder, including fatigue, widespread pain, fibromyalgia, depression, anxiety, and arthritic conditions.

IMPROVING ACCESS AND CARE

The committee's recommendations aim to build a strong base of knowledge about TMDs and to facilitate actions needed to ensure medical and dental care focuses on the overall health and well-being of individuals with a TMD (for an overview of the committee's recommendations, see the Overview of Recommendations insert). A substantial number of these recommendations focus on improving access and care for individuals with TMDs. TMDs have been compartmentalized as a dental issue for too long. Medical and dental care for TMDs should not focus just on treatment of specific conditions, but rather on the individual's total health and wellbeing. Coordinating care across medicine, dentistry, and other health professions will ensure quality care for individuals with TMDs.

The committee recommends developing Centers of Excellence for Temporomandibular Disorders and Orofacial Pain to provide comprehensive evaluations and treatment of individuals with TMDs and spur innovation in health professional education, clinical research, and data collection and analysis. The committee recommends that health professional associations should lead the development of tools for diagnosing and screening TMD patients, as well as tools for identifying each patient's individual level of risk. Primary care providers and dentists should use these tools to identify individuals who are likely to escalate from localized symptoms to systemic pain.

Health care professionals and others need to address the lack of evidence-based clinical practice guidelines for diagnosis, management, and referral strategies for individuals with TMDs. Current findings and new research efforts on TMD treatments should be tightly linked to the goal of producing evidence to develop clinical practice guidelines.

Health professional associations should also work with public and private insurance providers to create insurance models that are more consistent, fair, equitable, and appropriate for individuals with TMDs. The committee recommended that stakeholders such as the American Dental Association, The TMJ Association, and the Center for Medicare and Medicaid Innovation should conduct demonstration projects that would explore new delivery and payment models for Medicare, Medicaid, and the Children's Health Insurance Program to improve access, quality, and coverage for TMD care.

Further, efforts are needed to reduce the stigma that is often associated with TMDs. Research should be conducted to survey health care professionals about their biases, attitudes, beliefs, knowledge, and behavior regarding people with TMDs. The committee believes that efforts to increase education and awareness about TMDs across health professions as well as actions to improve the education of patients, families, and the general public are part of the efforts needed to help reduce the stigma of TMDs and improve patient well-being.

RESEARCH AND PROFESSIONAL EDUCATION

Despite investment in research directly and indirectly related to TMDs—most significantly in the field of orofacial pain, or pain felt in the face, mouth, and jaw—researchers have yet to unravel the causes or physical changes that lead to TMDs or to meaningfully translate research findings into improved clinical care practices. Fresh ideas and multiple disciplines are needed to advance TMD research to improve patient care. Given the number of individuals suffering from TMDs, there is a significant opportunity for NIH and other biomedical research institutions to drive increased funding to TMDs in order spark new research interest and discoveries.

The knowledge base for TMDs is still in its infancy and new resources are needed to spark advancements. NIH funding for TMD research falls largely within the NIDCR. NIDCR has one of the smallest research budgets of the NIH institutes, with a total budget of approximately \$461 million compared to the National Cancer Institute's \$5.99 billion for fiscal year 2019. The committee recommended that the NIH Office of the Director and NIDCR lead the creation of a National Collaborative Research Consortium with the input of a wide range of relevant stakeholders to coordinate, fund, and translate basic and clinical research discoveries.

Efforts to restructure patient care for TMDs should also include better education and training on TMDs for health professionals. The committee recommended that health professional schools and relevant medical and dental professional groups should strengthen curricula at all education levels in pain management, orofacial pain, and TMD care. The committee recommends the creation of a dental specialty in orofacial pain as a first step in recognizing and incentivizing specialized care of TMDs. The committee hopes any specialty would emphasize a care model spanning dentistry, medicine, and other health professions.

CONCLUSION

The temporomandibular joints are among the most frequently used joints in the body, often opening and closing thousands of times daily. Given the complexity of these joints and the wide variety in the 30+ temporomandibular disorders, there is no one treatment or care pathway for every TMD.

Improving care for individuals with a TMD should include

- developing comprehensive approaches to care that span medicine, dentistry, physical therapy, and other fields of health care — especially interprofessional and interdisciplinary efforts;
- willingness from health care agencies, organizations, and professionals to commit the resources needed to address this long-neglected and often dismissed area of health care; and
- openness and commitment to using and strengthening the evidence base on TMD treatment while changing practice as needed.

Some of the committee's recommendations can be accomplished rapidly with actions by key decision makers. Other recommendations are more aspirational and will require collaboration and commitment from multiple organizations and dedicated resources—including investments of time, funds, and innovative energies—to accomplish these goals.

**Committee on Temporomandibular Disorders (TMD):
From Research Discoveries to Clinical Treatment**

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