

Temporomandibular Disorders

PRIORITIES FOR RESEARCH AND CARE

ACTION GUIDE for Patients and Clinicians

What are TMDs?

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 health conditions.

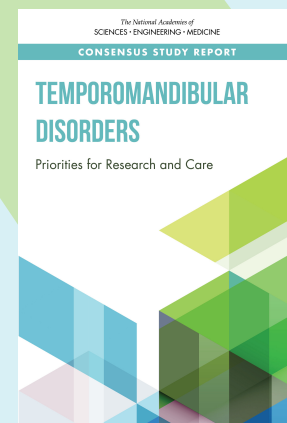
4.8%

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.

Living with a TMD can also carry a significant level of stigma. Patients with TMDs reported that they often do not feel believed by partners, relatives, and friends. Individuals with a TMD may hold back on sharing their symptoms, thoughts, or feelings with others because of concerns about stigmatization. Stigma can lead to poorer physical and psychological well-being, diminished self-esteem, and the feeling of the loss of dignity. Additionally, when seeking care, patients report that they were often sent from dentists to physicians and back again or were dismissed without care and with little information on suggested next steps.

A new report from the National Academies of Sciences, Engineering, and Medicine identifies many of the challenges that patients face in getting care for their TMD and offers actions clinicians and patients can take to improve health outcomes. Patients, their families, the general public, and health care professionals need evidence-based information about TMDs. This report recommends a number of steps patients and clinicians can take to improve care, including highlighting resources and tools for individuals with TMD symptoms and calling for the development of clinical practice guidelines based on an expanded evidence base on effective treatments.

To read the full report and view related resources, please visit nationalacademies.org/tmd



PATIENT EXPERIENCES

Many patients with TMDs face significant day-to-day challenges in living with a TMD, as well as challenges in accessing appropriate diagnoses and care.

Common issues raised by patients include:

Lack of coordinated care and abandonment



Individuals reported that they were often shuffled back and forth between clinicians in the medical and dental fields with little to no attention paid to a comprehensive approach to coordinated care.

Over-treatment/harmful treatment



Many patients reported having endured multiple TMD-related surgeries (in some cases more than 20), often with no resolution to their pain or with worsening symptoms.



Lower quality of life

Individuals with a TMD described how having a TMD has 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.



Additional Health Issues

Many individuals with a TMD note challenges with other conditions including fatigue, widespread pain, fibromyalgia, depression, anxiety, and arthritic conditions.



Cost

The financial burden of seeking and receiving care for a TMD can lead to significant out-of-pocket costs for patients and their families.

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STEPS YOU CAN TAKE TO IMPROVE CARE

Patients

Talk to your doctor

Patients have responsibilities to be engaged and to express their concerns. At the same time, patients have rights to expect listening, engagement, and communication from their health care professionals. Asking questions and requesting more information on treatment options can lead to improvements in outcomes, including better use of health care resources, lower health care costs, and increased use of evidence-based therapies.

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The Institute for Healthcare Improvement developed an Ask Me 3 campaign to encourage people to **ask three basic questions to their health care professionals**:

- 1 **What is my main problem?**
- 2 **What do I need to do?**
- 3 **Why is it important for me to do this?**

Be empowered to ask questions, seek person-centered care, and get multiple opinions

Patients have rights to ask for information that will help them make informed treatment decisions and to seek more than one opinion from health professionals and other patients. Patients should also know that they have a right to discuss concerns about their treatment options with their health care provider.

Connect with a patient support group

Peer support groups, both online and in-person, are vital to the work and outreach of many patient advocacy organizations. The TMJ Association and others have been active in this area and hosts on their website several ways to connect with others experiencing TMDs.



TMJ Association's online TMJ Café



TMJ Association's online support community



American Chronic Pain Association's peer support groups

Clinicians and Professional Associations

Provide Patient-Centered Care

Individuals with a TMD are more than their medical condition and quality-of-life factors are important. When prescribing treatments for TMDs, clinicians should consider a patient's overall well-being. Health care networks should also consider developing specialized TMD centers to better serve individuals with needs that span multiple types of care.

Develop and Disseminate Evidence-Based Clinical Practice Guidelines

Clinical practice guidelines should be developed and widely disseminated that provide evidence-based pathways for the initial recognition and stepped care management of TMDs as well as specialty care for patients with TMDs. Once clinical practice guidelines are developed, clinical performance measures should be deployed in quality improvement initiatives.

Continue Improving Knowledge and Skills

Clinicians should seek to improve their skills and knowledge related to TMD care in order to improve patient outcomes. These efforts should include the development of decision criteria for risk stratification to help identify patients who are likely to escalate from self-limiting and localized TMD symptoms to a systemic pain condition and then to high-impact pain.

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