



Advice for Dentists from Temporomandibular Disorder Patients: A Phenomenological Study

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ABSTRACT

Background: Despite increased efforts to improve the health of those with temporomandibular disorder (TMD), the focus remains on medical knowledge rather than patients' opinions and needs regarding quality of treatment and pain management.

Objectives: We aimed to identify what TMD patients want their dentists to know and do.

Methods: Open-ended questions were used to understand the perspectives of 6 TMD patients. Two researchers examined the transcripts using interpretive phenomenological analysis.

Findings: TMD participants consistently stressed the need for their dentists to listen and provide them with more advice and information to cope with TMD conditions. They also noted the need for dentists to be skilled in communications, particularly maintaining respectful doctor–patient relations and interpersonal communication.

Conclusions: Health care providers must acquire practical communication skills and expand their knowledge of TMDs to better support their patients. Improving relations between doctors and their TMD patients could result in positive health outcomes. The implications of this study will be to decrease medical crises and expensive interventions, provide better assistance to patients and refer them to other necessary health care professionals, an approach that will lead to lower care costs, more satisfaction and higher quality of life.

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Patients have a valuable perspective, which can be used in teaching patient-provider communication, pretesting health education material and improving health policy and administration.¹ Patient-reported outcome measures also have the potential to improve both quality and cost of care.²⁻⁵ Health care providers, particularly dentists, focus on pathological problems and are rarely concerned about holistic treatment for patients.^{6,7} In this study, we identify what temporomandibular disorder (TMD) patients want their dentists to know and be able to do to improve services and guide them to cope with their chronic condition.

TMD is a combination of clinical conditions that affect the temporomandibular joint (TMJ), the masticatory muscles and associated structures, such as the articular disc, capsule and retrodiscal tissue.⁸ These conditions create orofacial pain, which is defined as pain localized to the region in front of the ears, above the neck, below the orbitomeatal line or in the oral cavity. TMD limits lower jaw movement—causing stiffness or locking of the jaw or both. It affects 13.5–47% of the general population.^{9,10} TMD most often occurs as arthralgia or myofascial pain.¹¹ The prevalence of the latter is about 30% in patients with local pain complaints seen in primary care clinics and up to 85% in patients at specialized pain management centres.^{9,10}

About 50% of patients who suffer from TMD look for professional dental or psychotherapeutic care, and 33% of them will continue to suffer from moderate to severe pain, disability and psychological distress independent of the treatment received.^{9,10} The etiology of TMD is still not well understood, even though the annual cost for its treatment doubled in the last decade to \$4 billion.⁹ The poorly understood causes of TMD add complexity to its treatment, which includes physical, pharmacological, cognitive-behavioural and dietary therapies.¹¹

Unfortunately, health care providers who are concerned with alleviating pain take insufficient time to help their patients cope with day-to-day suffering.^{6,7} Understanding the perspective of persons who have TMD could improve the quality of future treatment.

Methods

Research Approach

A qualitative approach was chosen as most suitable for addressing this type of research, as it focuses on understanding the subjective experience of individuals.^{12,13} The exploratory nature of qualitative research enables the researcher to investigate the cultural, social, historical, linguistic and personal meanings and interpretations individuals give to their behaviour.^{12,13}

Interpretive phenomenological analysis (IPA) was selected as it emphasizes the experiences of the people participating in the research.¹⁴ IPA allows the researcher to learn more on the topic in question and gives him or her the chance to enter the participant's world, while acknowledging the participant as the expert.¹⁵ IPA is subject to a “double hermeneutic” or second interpretation, as the researcher makes sense of each participant, who is making sense of his/her own experience.

Patient Recruitment

Participants were English-speaking, ≥18 years old and with chronic TMD, confirmed by a TMD specialist (Table 1). They were contacted through referrals from specialists at the Jewish General Hospital, the McGill Student Dental Clinic and the Montreal General Hospital in Montreal, Canada, between September and November 2017. We aimed at a sample size of 6 participants.¹⁶ In IPA, the number of participants can be 2–25.^{14,17-18} Each participant provided informed consent.^{16,19}

In IPA, the goal is to reach a better understanding of the overall aspects among the participants lived experiences. According to Creswell,¹⁴ “It is essential that all participants have [similar lived] experience of the phenomenon being studied” (p. 155). Thus, sample size is based on the availability of suitable participants, not on their number.¹⁶ IPA studies are conducted on relatively small sample sizes, and the purpose is to get an almost homogeneous sample so that, within the sample, we can assess convergence and divergence in some detail.²⁰

Data Collection

We used semi-structured qualitative interviews¹⁶ with open-ended questions to obtain rich and detailed data for each participant (Table 2).²¹ The open-ended format allowed patients to provide detail and raise issues that were not otherwise covered by the interviewer's questions.²⁰

Data Analysis

The strength of IPA is its ability to remain adaptive to the interviewee's experience; thus, data analysis is not strict, procedural or rule-oriented.²⁰ Accordingly, we adopted the Van Manen²² “way towards human understanding” approach to data reduction and interpretation. Responses gathered during interviews (participant interaction during the interview) were familiarized and interpreted along with non-verbal clues, such as sighing and smiling. Similar responses were grouped, and key recurrent themes were identified. Data were compared within and between participants, and this process continued until no novel themes could be identified.

Ethical Considerations

Ethical approval was obtained from McGill University's Research Ethics Board Office, Montreal, Canada. All participants consented to a confidentiality agreement. Participants were identified by pseudonyms in the study.

Results

The findings captured the participants' comments regarding enhancing the quality of treatment that they hope to receive in the future. Responses are grouped under two themes. Regarding theme 1, "Dentists should expand their knowledge," participants emphasized the significance of expanding dentists' knowledge to get an efficient diagnosis and receive effective treatment (Table 3). The second theme was "Dentists need to develop their skills in terms of communicating with patients" (Table 4).

Discussion

The participants in this study suffered from misdiagnosis and consequent mismanagement of their cases, especially by dentists. They attributed many of the causes of their TMD symptoms to ineffective dental care. Moreover, the participants reported not getting practical advice about how to deal with these conditions and manage their pain effectively. Our results support previous findings that TMD patients are dissatisfied with the health care system.⁷

Misdiagnosis and multiple failed treatments are common among TMD patient populations; consequently, these patients go through multiple stages of dental processes that fail to eliminate their

symptoms, followed by referral to oral and maxillofacial surgeons for evaluation and treatment.²³ Some participants in this study reported suffering resulting from misdiagnosis, including tooth extraction, because the treating dentists mistakenly thought the orofacial pain was tooth pain. In addition, dentists prescribed medications that resulted in other serious health problems. Some participants said their ongoing orthodontic treatment was the cause of their TMD and cited mismanagement by their orthodontist. This finding confirms previous research showing that changes in the morphology of the TMJ could result from the constant force exerted by fixed repositioning appliances used in orthodontic treatment.²⁴

Good relations with health care providers are critical for effective patient-centred care and safety.^{2,3,5} High-quality relationships improve outcomes of care.²⁵ The relationship between doctor and patient must be based on open, sustained dialogue and sharing of information and knowledge.²⁵ A high-quality doctor-patient relationship is considered to be at the heart of medical and dental care.³ Factors, such as doctor shortages, wait lists, time pressure and financial constraints account for declines in good relations.³ Moreover, chronic or acute conditions, or both, affect patients' expectations of the care they will receive.³

Participants complained that dentists did not listen or provide effective advice or efficient follow-up consultation. Some participants felt that dentists' language was scientifically complex or unclear, which increased their anxiety. For example, oral health care professionals might suggest a "soft" diet to address TMD symptoms without explaining what that means or that its purpose is to change the diet to minimize masticatory efforts. Foods suggested by a doctor may still be too difficult for some patients to eat; a "soft roll," for example, requires greater masticatory effort to bite, chew and swallow than popcorn or chopped tomato, both of which have more fiber.²⁶

Table 1: Participant demographics.

Participant ID	Residence	Age (years)	Sex	Level of education	Occupation
Saddam	Montreal	51	Male	PhD	Student
Maryam	Montreal	22	Female	Undergraduate	Student
Jon	Montreal	29	Male	Master's	IT advisor
Noor	Montreal	25	Female	Bachelor's	Music teacher
Monika	Montreal	64	Female	Master's	Retired
Shanna	Montreal	39	Female	Bachelor's	Massage therapist

Table 2: Interview guide.

• Tell me about your experience living with TMDs (jaw pain), and what that does it mean for you?
• How long ago did your jaw pain begin?
• How has your pain affected your life?
• Have you had to change your diet because of this condition?
• Have you had to change the kinds of food you now eat to accommodate your pain?
• If yes, please explain in more detail.
• How has your pain affected your general health?
• Please explain.
• What are/were the effect(s)?
• How have you learned to manage these issues?
• How does living with TMD make you feel about your quality of life?
• Were your doctors understanding about your suffering?
• Did the doctors listen to your concerns reading the impact of TMD on your life?
• Did they offer any new or helpful advice?
• Is there anything else you would like to add on this topic?
Demographic questions:
• Where were you born?
• Where do you live?
• What is your age?
• Male/female?
• What is the highest level of education you have completed?
• What is your occupation?

Table 3: Theme 1: Dentists should expand their knowledge.

Participant	Response
Saddam referred to the importance of expanding dentists' field of learning beyond only treating the issue.	<p>"The way the dental education is done over the world is it's fairly isolated from the scrutiny of your peers. Like you are doing in medical school where there will always be a head of a department that will look over what we're doing for many years, and they will criticize, and then you have to present to your peers. And then you will get that as a dentist you're just alone, and you are honestly even if you want to do the best and you, and if you are making a mistake you don't know. And that's the fallacy because you don't know, and nobody will tell you. You will just start to persist in what you're doing [wrong]. . . . And</p> <p>because nobody will tell you that you were ever wrong you start to believe that you are really special as a person and you are way more educated as you know. All it needs to be known. . . . It's a bias, it's a bias that's present all over the place. But the environment is very conducive for this bias to appear very early and to expand. So, because dentists will not read more because of that, because they think they know enough, which is totally false. They could listen more and just by listening they will be able to find out lots of things like this."</p>
Saddam	"I think that, for example, after you learn about doing prosthetic work or doing fillings, the consequences of doing a bad filling not only in the word failure but kind of expand into it and what is evolved on it and long-term things and expand them more. And though they are mentioned in the books they are not really emphasized exactly."
Saddam suggested a solution to resolve the lack of knowledge problem.	"So, I think making or introducing the sequences of TMD in the curriculum and also into the residency should be compulsory. This things and rotation seen in hospital at least in the digestive department. So were anything. Or just bring a different level of education and then a different layer of quality of the medical product. And sometimes having a better understanding of what's urgent to be done or what should not be done."
Noor	"I think that the doctor should be aware of full information, a good-enough information about their TMD patient's diet."
Saddam and Noor were also misdiagnosed in the beginning stages of experiencing TMD	<p>Noor: "A doctor did not really know what it was. They thought it was a problem with my wisdom tooth, and they suggested like extraction of my wisdom teeth. But I wasn't too sure because I read about a few cases online about this jaw pain, and I learned that like it's not necessarily wisdom teeth. I met a few doctors in my home country and then they said like it's nothing to do with your teeth because they're like straight and fine, and one of the doctors said it was TMD. So, that's how we started. . . . I would feel not really motivated, and I would feel a little drowsy and down."</p> <p>Saddam: "This is happening for the last ten years and because it was a mismanaged case, so because the teeth moved around, and I don't have the same contacts, and the prosthodontic cannot be done finally. I got into this temporomandibular joint pain and the experience of living with it. It's not fun because sometimes you start to have pains and creaks and you feel that the bite it's not in the right place, and it's just the thing that decreases the joys of life."</p>
Shanna believed mismanagement of her orthodontic treatments led to her TMD jaw pain. She was also unsatisfied with her treatment, which she stopped after seven years, refusing to finish.	"I was going to the orthodontist that I had, who was working a little too aggressively in my mouth, and my teeth were very cramped when he did the orthodonty. I don't think he did it right. And one of his colleagues told him this is too aggressive and, considering the way that her mouth is, it's not the right path to take. But the treating doctor didn't take that into account. So, after seven years and without having finished my treatment, I stopped it because not only was it too aggressive, but it also created more problems such as periodontitis."

Table 3 continued ►

Participant	Response
Maryam expressed feeling miserable and that nothing helped to improve her TMD condition.	"It really started when I was in elementary school. I noticed that my jaw would click when I would eat, and it didn't bother me at the time. It was just like something that was like audible like my friends could hear it when I ate even. But then over time about a year ago it started to move when I would try to eat. And then you would have to push past that, and then when I would push past it, it was certain to hurt. And two months ago, it started where no matter what I ate and what I've been on too it would hurt so bad that I couldn't really eat properly. So, that's been going on for about two months now. And I got my wisdom teeth out two weeks ago. Just fly home, and I've been away for a bit, and even then, now I tried to eat again, and it still hurts. Nothing has really helped."
Jon expressed that he had not received effective treatment for his TMD.	"I would say I have started having this TMD quite recently, about maybe a year-and-a half ago, and it's actually become really worse... I would like to say the pain is really bad. I've never had it before. And I didn't, you know, go with real treatment when I got dental appliance and so then I was biting a lot. So, I'm using that. That was helping me. But two or three weeks ago my condition started to deteriorate once again. So, I started to feel pain in my joint, and that is affecting a lot of aspects in my life..."
Shanna suggested a practical tool in the format of a TED Talk video to provide advice to assist TMD patients who change their diet.	"I think something that might be good is maybe like a quick video. You know, you look at it on your off time. It takes five minutes maximum and all the information that will help a lot. So, this TED talk a little informative how you are curious things. Something like that for TMD would be great. Yes, I don't even know if it exists. It probably does because TED is just awesome. Yeah, but for our problems here, that might be an interesting solution for us."

Table 4: Theme 2: Dentists need to develop their skills in terms of communicating with patients.

Participant	Response
Saddam referred to the importance of the quality of dentists' communication with patients and stressed the importance of listening to the patients' complaint by the dentists.	"Doctors should listen, listen, listen more and more. They don't listen. They are missing a lot of information that will be helpful even in their treatment plan. They see the problem, but they don't really listen. Usually, that is done by an assistant. That's the message for the dentist. Listen more. Because if I told them "learn," the word they think they know, that's the problem."
Maryam and Noor said that they preferred health care providers to give more time and attention to patients and schedule more follow-up consultations. They believed providing patients with practical guidelines may relieve them of their fears. These guidelines could be supplied to patients through booklets.	Maryam: "Yeah, it would have been good to get like just have a little bit more time or have a follow-up on site thought of questions. So, I just wish that just in general like it would be nice to have more information about what jaw pain can make, how jaw pain can affect your life, and especially being as young as I, and what it might mean in the future. I was really upset about that. Also, what is the pain that's going on and how is it going to affect your life. It would be nice to have the booklet saying how you can alter your dietary needs and maybe just make suggestions on how to avoid making it worse."

Table 4 continued ►

Participant	Response
<p>Maryam also felt the language the dentist used was too scientific, making it difficult to understand what her diagnosis was and the treatment plan, thus increasing her state of loss and fear.</p>	<p>"I felt like again everything was so rushed. . . They kind of just told me, oh it's osteoarthritis. And for my facial pain, use naproxen. I was like what does that even mean? I didn't even know. Do I have arthritis everywhere, or is it just my jaw? How do you know it is in my jaw? I just felt like I didn't really get anything explained to me properly."</p>
<p>Noor was equally upset about the lack of advice she received from her dentist.</p>	<p>"Because most of them, what they tell me is just go for physiotherapy."</p>
<p>Noor emphasized her wish for more information regarding TMD conditions.</p>	<p>"I wish I had more information....And in terms of that, doctors and students who are studying this should know not just telling people that there is a problem such as this and many people have a disease, but they don't realize it."</p>
<p>Noor added that it is important to publish more articles in this field and raise people's awareness about this issue because a large number of people have a TMD but simply do not realize it because they lack knowledge about it. She hoped to see more advice about this. Otherwise, the situation may worsen.</p>	<p>"For example, advertising this part of the study is too public because I read online that like many people these days, like 23% of the population have this problem because of stress or food or the style of diet, whatever. There are so many causes and many people how they like even my friends they have it, but they don't really know about it. So, I mean this condition never going back, so I have to maintain this, don't go worse than this, I have to get some treatment done [surgery]. So, I think people should be more aware of this. So, in the end, the doctor should be able to suggest an alternative and effective style of diet. . . . At times I get problems, and even like when I'm chewing soft food, I get a pain. So, I wish the doctors could tell me more about it. How my jaw operates when I chew something hard, a steak or something. It is like I want to know what's going on. If they could tell me, then I would be more careful, so I can have my favorite food without causing the pain."</p>
<p>Monika expressed dissatisfaction with lack of communication and follow-up in stating.</p>	<p>"First of all, patients see a doctor, and they go back to emergency, and it is not the same doctor. Come out with a new diagnosis, get a new kind of medication, go to the pharmacy get a medication. That is worse than the disease itself."</p>

Conclusion

This study suggests that health care providers must acquire effective communication skills and expand their knowledge of TMDs to better support their patients. Improving the relationship between doctors and their TMD patients could result in positive health outcomes.

The uncertainty surrounding diagnoses negatively affects TMD sufferers' daily lives.

TMD diagnoses must be initiated at the first point of contact.²⁷ This study elucidates the need for health care providers to be attentive to the broad effect of TMD conditions on patients' lives and the need to initiate conversations with patients—and listen to them. Appropriate and timely advice is also needed to assist patients in managing their chronic conditions. Health care providers who have enhanced communication and interpersonal skills tend to discover problems earlier, prevent medical crises and expensive interventions, provide

better assistance to patients and refer them to other necessary health care professionals. This approach leads to lower care costs, greater patient understanding of health issues, more satisfaction, higher-quality outcomes and better adherence to treatment and overall quality of life.⁶

Limitation of this Study

Our findings are not generalizable to other jurisdictions with political, social, cultural and health care systems different from Quebec's. Nevertheless, where similarities exist, our findings may be transferable to other provinces or countries. The study focused on patients' perspectives and experiences, and did not address the perceptions and opinions of health care providers. Further research might explore dentists' and health care providers' views to gain their insights into this topic of concern.

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