

# Treatment Seeking and Self-Constructed Explanations of Pain and Pain Management Strategies Among Adolescents with Temporomandibular Disorder Pain

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**Aims:** To explore adolescents' explanations of their temporomandibular disorder (TMD) pain, their pain management strategies for TMD pain, and their treatment-seeking behavior. **Methods:** One-on-one interviews were conducted with 21 adolescents aged 15 to 19 years who had TMD pain and followed a semi-structured interview guide. Subjects were strategically selected from patients referred to an orofacial pain clinic. All participants had been examined and received a pain diagnosis based on the Research Diagnostic Criteria for TMD. The interviews focused on the adolescents' experiences of TMD pain, their strategies for handling pain, and how they seek care. The interviews were recorded, transcribed verbatim, and analyzed using qualitative manifest content analysis. **Results:** Qualitative manifest content analysis revealed two categories: (1) self-constructed explanations, with three subcategories (situation-based explanatory model, physical/biologic model, and psychological explanatory model); and (2) pain management strategies, with four subcategories (social support, treatment, relaxation/rest, and psychological strategies). Adolescents used physical activities and psychological and pharmacologic treatment to manage pain. Reasons for seeking treatment were to be cured, to obtain an explanation for their pain, and because their symptoms bother others. **Conclusion:** Adolescents living with TMD pain develop self-constructed explanations and pain management strategies. With access to these descriptions, dentists can be better prepared to have a dialogue with their adolescent patients about their own explanations of pain, the nature of pain, and in which situations the pain appears. Dentists can also explore adolescent patients' pain management strategies and perhaps also suggest new treatment strategies at an earlier stage. *J Oral Facial Pain Headache* 2016;30:127–133. doi: 10.11607/ofph.1450

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**T**emporomandibular disorder (TMD) pain in adolescents is common and has a clear impact on daily living.<sup>1–3</sup> The etiology of TMD pain is not well understood but is considered to be multifactorial and to include factors that predispose subjects to TMD pain, factors that trigger pain, and factors that maintain pain. Risk factors for the onset of TMD in adolescents are similar to those for the onset of other pain conditions in adolescents as well as to those for the onset of TMD and other pain problems in adults.<sup>4</sup> LeResche et al<sup>4</sup> found that being female, having negative somatic and psychological symptoms, having a number of other pain complaints, and dissatisfaction with life predicted TMD pain in adolescents. Several studies have shown an association between headache and TMD, and in many cases, headache was found to precede TMD pain in adolescents.<sup>5</sup>

The prevalence of TMD pain in adolescents is between 2% and 6%.<sup>6,7</sup> It is also more common among girls than boys.<sup>7</sup> TMD pain often fluctuates over time, although some adolescents report continuous pain.<sup>8</sup>

The majority of adolescents with TMD pain think they need treatment.<sup>2,3</sup> However, only about a third of adolescents reporting TMD pain once a week or more receive any treatment at all.<sup>7</sup> Hirsch et al<sup>1</sup> found that increased experience of TMD pain correlated with increased impairment, doctor consultations, and analgesic consumption.<sup>1</sup>

In adults, factors such as frequency of pain, duration of pain episodes, pain intensity, and disability are associated with care-seeking behavior for orofacial pain. When pain lasted more than 3 months, treatment seeking doubled.<sup>9</sup> Rollman et al<sup>10</sup> found that in addition to pain intensity, fear of jaw movements plays an important role in the decision to seek care for orofacial pain. In a qualitative study that compared adults with TMD pain who sought care with those who did not, the findings showed that the groups differed mainly in personality characteristics such as catastrophizing, pain management, assertiveness, critical attitude toward health care, and confidence in medical care. The authors also found that inadequate referrals may play a role in care seeking.<sup>11</sup> When adolescent sufferers of TMD pain seek treatment, clinicians often find their symptoms difficult to diagnose.<sup>12</sup> Durham et al<sup>13</sup> also observed that clinicians experienced difficulties in diagnosing and managing TMD in adults. A qualitative study in adults with TMD<sup>14</sup> showed that lack of a diagnosis caused uncertainty in patients over the nature of their pain complaints. This uncertainty negatively impacted patients' daily lives. Difficulty obtaining a diagnosis meant that they often were searching for other explanations for their signs and symptoms.

Two studies found that children and adolescents with chronic pain indicated that the quality of their interactions with health care professionals was very important to them.<sup>15,16</sup> Using qualitative methods, Dell'Api et al<sup>17</sup> found that children and adolescents with chronic pain perceived that their interactions with health care professionals influenced their experience of chronic pain. They reported feeling misunderstood, disbelieved, and abandoned. Meldrum et al<sup>18</sup> reported similar results in a qualitative analysis (grounded theory) of adolescents with recurrent pain, finding that participants perceived that their physicians had a lack of understanding and were not listening to them. Carter<sup>15</sup> pointed out that the best evidence for understanding a young person's pain comes directly from that person.

Functional limitations stood out as the predominant theme in a qualitative study of a group of 45 children and adolescents, aged 10 to 18 years, with chronic pain, mostly headache and myofascial pain. Various strategies for pain management were identified; "getting on with things"—ignoring the pain and trying to keep going—was the most common strategy.<sup>19</sup> The authors found that adaptive children continued to participate in many activities and were more likely to realize that focusing on the pain would heighten their perception of pain. Stressed children continued to function but were highly focused on their pain and the difficulties of living with it.<sup>19</sup> In a qualitative study, Carter et al<sup>16</sup> found that adolescents

with chronic pain internalized the advice to stay relaxed when pain returned and that this helped them to an extent. They coped with pain by using their own strategies.

An earlier study found that "adolescents with TMD pain live with recurrent pain; physical problems and daily demands form a vicious circle that causes adolescents to oscillate between hope and despondency."<sup>20</sup> There is, to the authors' knowledge, very little research about adolescents' own explanations of their TMD pain and their strategies for handling it. Hence the aim of this study was to explore adolescents' explanations of their TMD pain, their pain management strategies for TMD pain, and their treatment-seeking behavior.

## Materials and Methods

This study used qualitative manifest content analysis with an inductive approach. An explorative and descriptive design was chosen to further investigate adolescents' experience of the phenomenon of TMD pain. The original material was very rich, and after coding the data, the categories "pain is recurrent," "physical problems and daily demands form a vicious circle," and "mood oscillates between hope and despondency" were found to have been presented in an earlier report.<sup>20</sup> The remaining data were analyzed in the present study.

## Participants

The study sample, described earlier,<sup>20</sup> was a strategic selection from a convenience sample, 21 adolescents aged 15 to 19 years. Of the subjects, 19 were girls (between 16 and 19 years old) and 2 were boys (both 15 years old). The participants were selected from the same population as a previous quantitative study of 587 adolescents.<sup>3</sup> The 21 adolescents had been referred to an orofacial pain clinic. The patients were examined according to the Research Diagnostic Criteria for TMD.<sup>21</sup> They were chosen with the intention of representing as many aspects as possible of the variety of TMD-related current pain problems: myofascial pain with different locations, painful clicks and catches, and arthralgia. Together, the participants represented the range of patients usually referred to a specialist clinic.<sup>20</sup> To be included, subjects needed to be (1) adolescent, aged 12 to 19 years; (2) experiencing TMD pain once a week or more; and (3) able to express themselves verbally.

All participants received oral and written information about the study. They were informed that study participation was voluntary and that they could stop the interview at any time. All patients, or a parent if the patient was under 18, signed an informed-consent

form. The Ethics Committee of the Faculty of Health Sciences at Linköping University approved the study (daybook number 75/04).

The first author is a TMD specialist with much clinical experience treating adolescents with TMD pain and therefore is familiar with the context. The second author has no such experience; she is a nurse researcher with significant experience in research with qualitative methods. According to the method, preunderstanding must be put aside during analysis, otherwise a prejudiced meaning could influence the result. Before analysis, the second author examined the data for credibility to verify that the interviews contained meaningful data. Since the interviewer was inexperienced in performing this kind of research interview, the second author examined the data for credibility, ensuring that the data were of such length and depth that the interview texts were suitable for analysis, and discussed the interview technique with the first author.<sup>22</sup>

**Interviews**

The first author performed all the interviews by using a brief, semi-structured interview guide that included the following topics to be covered:

- Life with TMD pain
- Situations with TMD pain
- Impact of TMD pain on life
- What patient hopes for
- Care sought and why

The interview questions were open-ended to allow the participants to express themselves in detail, ie, their experiences of living with TMD pain,<sup>20</sup> including how they handle pain and how they seek care. The interviewer asked probing questions (eg, Can you tell me more? Can you give me an example? How

**Table 1 Example of the Steps From Code to Category**

Code	Subcategory	Category
It just is there.		
It might be an entire situation.		
Pain coexists with other disorders.		
When I am stressed.	Situation-based explanatory model	
I get tense.		
I compete.		
I clench my teeth when I am stressed.		
It becomes a vicious circle, stress and pain.		
Maybe it's related to the bite.	Physical/biologic explanatory model	Self-constructed explanations
When I talk and chew.		
When I am tired.		
When I sleep on my stomach.		
It might have been when I got hit.		
There's no limit to my expectations.		
Expectations of myself (and others).		
I don't manage to help myself but help others first.	Psychological explanatory model	
I don't live up to expectations.		
I am disappointed/dissatisfied with myself.		
Lack of control.		
I get stressed by others and my own expectations.		

did you feel?) to follow up, clarify, and deepen the participants' answers.

In most cases, the first author interviewed the participants shortly after their initial clinical examination; some of the adolescents, however, had already received treatment at the time of the interview. The interviews took place in a separate, nonclinical room in the clinic office. The interviews were recorded on a digital recorder, and a clinic secretary transcribed them verbatim. The interviews lasted 22 minutes on average. The data files were then coded and archived in the database.<sup>20</sup>

**Data Analysis**

A qualitative content analysis was performed on the interview transcriptions<sup>23-25</sup> according to the following procedure. Initially, the first author listened to the interview recordings and read through the transcripts to get an overall impression and sense of the material. The first author analyzed the entire text to identify all meaning units related to the research topics. The content of each meaning unit was condensed and reformulated by removing unnecessary words while still preserving the essence.<sup>23,24</sup> After the first author began condensing the meaning units, the second author read four of the interviews and both authors then discussed the condensing procedure and made revisions. The first author alone condensed the remaining meaning units. A researcher who was not involved in the data collection evaluated the credibility and trustworthiness of the authors' interpretations (so-called peer-debriefing) by reading three randomly selected interviews. He verified that the meaning units were grounded in data, and he compared the extracted and condensed meaning units and found they were consistent.<sup>26</sup> Table 1 shows an example of the steps in the manifest analysis, from code to category.

After this review, both authors analyzed the condensed meaning units separately and open-coded them, one by one, while asking the following questions: What are they actually talking about? What does it mean? What else is similar to this? When the condensation procedure of the

**Table 2 Overview of the Categories and Subcategories**

Category	Subcategories
Self-constructed explanations	Situation-based explanatory model
	Physical/biologic explanatory model
	Psychological explanatory model
Pain management strategies	Social support
	Treatment
	Relaxation/rest
	Psychological strategies

total data was finished, the selection of data presented in the first publication<sup>20</sup> was made, and the meaning units related to explanation of pain and pain management strategies for TMD pain and of treatment-seeking behavior were put aside for future analysis, ie, the data analyzed and presented here. Thereafter, the two authors grouped the meaning units into subcategories based on similarities and differences, and then compared and contrasted them with the text to ensure credibility.<sup>22</sup> All meaning units were included in the analysis and fitted into the categories. Manifest analysis with descriptive codes and subcategories that were close to the text was used. The codes in each category all had common features, though they were expressed differently by different participants and this pointed to subcategories, or variations within the categories. Both authors discussed the emerging interpretations and the groupings until consensus was reached in order to enhance the thoroughness in the interpretation of the text and to secure the best possible account of the adolescents' views.

**Results**

The categories that emerged from the content analysis of the interviews were "self-constructed explanations" and "pain management strategies" (Table 2). The categories as well as the participants' treatment experiences are presented below with some representative quotations from the interviews.

**Self-Constructed Explanations**

TMD pain is a personal and often complex experience, and adolescents construct explanations for their pain that involve coexistence with other disorders, stress, physical circumstances, and psychological aspects such as expectations of themselves, or others' expectations, that are difficult to live up to. The analysis showed that the participants (P) constructed their own explanations for their TMD pain and that they might present more than one explanation.

When the codes were clustered in this category (self-constructed explanations), three subcategories were identified as causes of pain: (1) situation-based, (2) physical/biologic, and (3) psychological (Table 1).

**Situation-based explanatory model.** Adolescents reflected on the fact that they had TMD pain, on why that was so, and on the possible causes of pain. Because pain occurred in situations when they felt stressed, had a headache, and felt tense, some thought these phenomena to be related:

*When my headache was worst, it was always in school, because we had so much to do. I was always tired then. I think they were connected. (P-13)*

In this subcategory, the adolescents expressed that the pain is just there, it might be the entire situation, and that the pain coexists with other disorders. The pain comes when they compete, and the situation becomes a vicious circle with stress and pain reinforcing each other.

**Physical/biologic explanatory model.** Adolescents in the study also suggested physical or biologic causes for their pain. They reflected on the fact that they had more pain when they talked, ate, chewed, or got tired, or while sleeping on their stomach. This subcategory included, for example, the code "It might have been when I got hit" (Table 1). Some thought the pain might be related to their bite, as in the example below:

*They said that my overbite also contributes. Mom's bite isn't good either and she has clicking sounds. My brother and dad have very good bites, and they have never had any problems. So maybe it's related. (P-2)*

**Psychological explanatory model.** This subcategory included codes mostly related to expectations, including high expectations of oneself and fear of failure, and reflected the adolescents' awareness of how they were affected by stressful situations (Table 1). The interviewees talked about their expectations of themselves and others, about not living up to these expectations, and about feeling dissatisfied with themselves. For example:

*I have high expectations of myself. I'm the one who gets myself wound up, and then I get stressed, whatever I do. I have myself to blame. (P-5)*

**Pain Management Strategies**

Adolescents develop pain management strategies in various ways. One person can use more than one strategy. The analysis revealed four subcategories of pain management strategies: (1) social support, (2) treatment, (3) relaxation/rest, and (4) psychological

strategies. Each of these strategies can be both active and passive.

**Social support.** Two codes were identified, “support from the family” and “I tell someone,” which were sorted into this subcategory. Telling someone about how it feels improves the pain. The following quotation illustrates the importance of support from others:

*If I had not had animals, family, and a boyfriend, I wouldn't have survived. (P-4)*

**Treatment.** This pain management strategy included the codes “physical activities,” “psychological treatment,” and “biologic/pharmacologic treatment.” The adolescents tried a variety of treatments, including self-care and professional care, with which they had varied experiences. Physical activities included physical therapy, massage, acupuncture, and drinking water. Several adolescents had tried splint therapy; most of them found it helpful but one did not. Some tried relaxation tapes as treatment and found that they worked fairly well; others tried reminders, such as displaying red dots all over their house, to make them think about relaxing their jaws. These strategies were coded as “psychological treatment.”

The strategy “biologic/pharmacologic” treatment included the use of painkillers, sedatives, and keyhole surgery. As one interviewee said:

*A lot of Panodil [paracetamol], perhaps more than I should have. (P-2)*

Seeking treatment is a pain management strategy in which the content reveals that adolescents take control of the situation and seek help for TMD pain. Adolescents in the study gave many reasons for seeking care and some of them had difficulties finding the right caregiver. Pain was an important reason for seeking care, as was the desire to have an explanation for the cause of pain. The codes related to treatment-seeking behavior were “to be cured,” “to get an explanation,” and “because it bothers others.” The data revealed several reasons that subjects sought treatment. Some did so because they had a pain problem that was not resolving by itself or was getting worse. Others sought care because not knowing the cause of pain scared them and they wanted an explanation.

*I got panic-stricken. I didn't know what was going on. (P-2)*

Still others said they wanted to get rid of the pain. Some adolescents also said that the clicks and catches in their jaw joints bothered other people.

When the analyses explored what the adolescents related about their treatment-seeking behaviors, the two codes “sought professional care” and “did something myself” emerged. Data revealed that it was not obvious to the subjects how and where to seek help. Adolescents and their parents disclosed diverse experiences seeking treatment. Some sought help from a physician or a dentist. A common experience was that they must do something themselves, and some of them also got support from others to seek care.

*It was my mom who said I should come here. I had no idea where I should go. (P 1)*

Some requested a referral to a specialist. It was not difficult to get the referral, but they had to wait before they got there.

**Relaxation/rest.** Adolescents found various ways to relax and strategies for managing the jaws. Examples of these strategies included going to bed, relaxing, chewing slowly and taking small bites, doing jaw exercises, being careful, or using the jaw as little as possible. This strategy subcategory included “I try to relax” and “be careful with the jaws.”

**Psychological strategies.** The two codes “I try not to think about it” and “lower expectations” were identified. The strategy of trying not to think about the pain, ignoring it, and thinking of something else also included statements about continuing to do usual activities and trying to forget the pain. The “lower expectations” code highlighted the adolescents’ self-awareness and resistance to expectations.

To summarize, experiencing TMD pain leads adolescents to develop various pain management strategies including seeking support from others, relaxation, being careful with the jaws, and trying not to think about it. While the subjects used a variety of treatment strategies, some reduced pain and others did not.

## Discussion

This study explored and described how adolescents live with TMD pain by focusing on how they try to understand their TMD pain, and on why and how they seek care. They try to understand the TMD pain and put their problems in context. The study’s one-on-one interview method helped to amplify the individual patient’s voice.

An earlier study reported an analysis of parts of the data and used qualitative manifest and latent content analysis.<sup>20</sup> The present study analyzed the remaining data by using qualitative manifest content analysis, since insufficient depth was found for latent

analysis in this study.<sup>24</sup> Other methods (eg, repeated interviews, focus groups, or a questionnaire) might have yielded further depth.

Because the interviewer was familiar with the context, it was easier to have a dialogue with the interviewee, follow the dialogue, and ask probing questions; that is, to achieve depth in the data that would not have been possible otherwise. The second author is a person without that preunderstanding, who saw only the text data and helped to ensure that the main thread was preserved.

A limitation of qualitative manifest content analysis is that it is purely descriptive; it describes what is there but may not reveal underlying motives as would a latent analysis, which was not possible. In this study a couple of the young interviewees had difficulties expressing themselves; they seemed unused to talking about pain and even lacked words for their own experiences. This made data analysis difficult, but it still was important to give voice to the individuals. The informants' difficulties in expressing themselves not only made analysis difficult but could also have a negative impact on their contact with potential caregivers. It is an advantage of the study that the interviewer listened to and described the individual's voice, and this approach may help caregivers meet and talk with adolescents and parents in new ways. It is important for caregivers to understand what is most important to their patients, what patients believe about their pain, and what they think will help them get better, as this will probably influence their receptiveness to information, commitment to changing their behaviors, adherence to prescribed medications, and other important treatment considerations. This may also result in a deeper dialogue and a deeper understanding. The present study provided other information, helping the interviewer to interact with the patients. In this context one can also emphasize the responsibility of the individual caregiver to make it possible for young people to make their voices heard.

When pain is chronic, is poorly understood, and has lost its usefulness as a signal to warn us about harm, it can itself become dangerous.<sup>27</sup> Adolescents in the present study had self-constructed explanations to help them understand their experience of pain, and these may have led them to different pain management strategies.

The analysis in the present study distinguished between "strategy" and "treatment," where treatment is a prescription by a professional. The findings revealed that adolescents developed a variety of pain management strategies. One person can have and use several strategies. One of these strategies was "social support," in which the adolescents expressed the importance of family and people to whom they could talk. A qualitative study among adolescents

with chronic illness, some with pain, also showed that most adolescents felt that talking to someone, family or friends, was helpful.<sup>28</sup>

In the present study, psychological strategies were common, such as trying not to think about the pain, focusing on something else, or trying to ignore the pain. It has been shown that psychological treatment can produce generally positive results in adolescents.<sup>29</sup>

Research has also found that relaxation can be an effective treatment for adolescent headache sufferers.<sup>30</sup> The present study showed that adolescents used relaxation strategies. Adolescents also practiced being careful with their jaws. This and other coping strategies were similar to those that Aaron et al<sup>31</sup> found to be used by adults in an electronic diary study. They found patients were more likely to use almost every type of strategy at times of increased pain: activity reduction, relaxation, seeking emotional support, and limiting jaw use. The present study found similar results, with adolescents using pain-coping strategies and continuing with activities despite pain and discomfort.

Splint therapy has been found to help a majority of adolescents with TMD pain<sup>32</sup> and was also a treatment approach in this study. Adolescents expressed similarly mixed experiences regarding physical therapy and painkillers. Which treatments were helpful seemed to be highly individual.

Durham et al<sup>33</sup> found that patients sought help but found no answers, and they suggested that improving communication between the caregiver and the patient may be the key to decreasing psychological distress over the cause of the pain and may help the patient to enlist social support. That is probably true for adolescents as well.

Several factors affect adolescents' experience of pain, including biologic processes, psychological factors, and the social context. In order to better understand and care for children with chronic pain, it is essential that caregivers provide them with the opportunity to communicate their unique personal experiences of pain<sup>17</sup> and listen carefully and respectfully to what they say.

## Conclusions

With access to descriptions of adolescents' self-constructed explanations of their pain and pain management strategies, dentists can be better prepared to meet and to have a dialogue with adolescent patients about their own explanations of pain, the nature of pain, and in which situations the pain appears. Dentists can also explore adolescents' own pain management strategies and perhaps also suggest new treatment strategies at an earlier stage.

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