## Adolescents with Temporomandibular Disorder Pain—The Living with TMD Pain Phenomenon

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Aims: To acquire a deeper understanding of adolescents' experiences of living with temporomandibular disorder (TMD) pain. Methods: Twenty-one adolescents with TMD pain, aged 15 to 19, were strategically selected from a group of patients referred to an orofacial pain clinic. The patients were examined and received diagnoses per the Research Diagnostic Criteria for TMD. One-on-one interviews that followed a semistructured protocol focused on the patient's experiences of living with TMD pain. The interviews were recorded and transcribed verbatim, followed by content analysis to obtain a deeper understanding of adolescents' experiences living with TMD pain. Results: Content analysis led to the overall theme "Adolescents with TMD live with recurrent pain; physical problems and daily demands form a vicious circle that causes adolescents to oscillate between hope and despondency." The latent content forming the theme is grounded in three categories that evolved from 13 subcategories. For instance, five subcategories—headache; headache on awakening; jaw and tooth pain; constant thoughts of pain; and popping, cracking, clicking, and locking—formed the category that was labeled TMD pain is recurrent. The latent interpretation, ie, the meaning, of this category was that adolescents with TMD pain constantly thought about the pain, even when it was absent. Con*clusion:* TMD *pain is a substantial problem for affected adolescents* and has consequences for all aspects of their lives. In this study, the adolescents were able to talk openly and introduce issues outside of the interview protocol. Qualitative analysis deepens our understanding of the adolescent patient with TMD pain. J OROFAC PAIN 2011;25:107-116

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Temporomandibular disorder (TMD) pain is common among adolescents. Epidemiological studies have found prevalence rates of 2% to 6%, with more girls than boys reporting pain.<sup>1-3</sup> The incidence of selfreported pain among adolescents increases with age.<sup>4</sup> LeResche et al<sup>2</sup> found no gender differences, but Nilsson et al<sup>4</sup> observed a higher incidence among girls than boys. For most adolescents, the pain pattern fluctuates over time. But a smaller group of individuals have continuing pain for several years, and the vast majority of adolescents with more longstanding TMD pain problems are girls.<sup>4</sup> The comorbidity between tension-type headache and TMD pain is well-documented.<sup>5-8</sup> Several studies have observed that TMD pain in adolescents has a potential impact on daily living.<sup>5,9,10</sup> Analgesics are taken once a week or more by 22% to 25%,<sup>5,9,10</sup> and one out of four are absent from school once a month due to TMD pain.<sup>5,10</sup> The Nilsson et al<sup>10</sup> population-based case-control study among 587 adolescents aged 12 to 19 in a Swedish county found the impact of TMD pain to be significant in this age group. Psychosocial status scores measured as depressive symptoms scores and somatic complaints were higher in adolescents with TMD pain than in nonaffected adolescents. Limitations in jaw function were also considerable in the TMD pain group.<sup>10</sup>

Hirsch et al<sup>9</sup> compared orofacial pain with other pain complaints (headache, stomach pain, and back pain) for impairment and health-care utilization in a sample of 1,011 adolescents in Germany. Fifteen percent of adolescents with TMD pain visited a doctor/dentist.<sup>9</sup> Despite differences in prevalence, the treatment demand was comparable for orofacial pain and the other pain complaints.

Two Swedish studies<sup>5,10</sup> found a perceived need for TMD treatment in the majority of adolescents who experienced TMD pain once a week or more. The higher treatment need in the Swedish studies might be due to differences between the studies in measuring pain frequency. In the German sample, pain frequency was defined as "at least once during the last month" and, in the Swedish studies, "TMD pain once a week or more." The overall impact of TMD pain on behavioral and psychosocial factors appears to be higher in girls than in boys.<sup>10</sup>

Previous studies have shed light on various aspects of TMD pain through quantitative methodology. Analyses have been generally based on questionnaires. One limitation of such instruments is the lack of a mechanism that would allow individualized answers, ie, allow the interviewee to introduce outside issues. "Pain is whatever the experiencing person says it is, existing whenever he says it does."<sup>11</sup> If pain, as it is described, "is a personal, private experience to which no one else has access,"<sup>12</sup> the question is how we can get deeper knowledge about such an experience.

Quantitative research observes patients on a group level. But all patients are unique and the third cornerstone in evidence-based medicine—patient values—is often neglected. Patient values are the unique preference, concerns, and expectations each patient brings to a clinical encounter that must be integrated into clinical decisions if clinicians are to serve the patient.<sup>13</sup> Qualitative research methods can contribute to our knowledge by deepening our understanding of the experiences of the individual teenager living with TMD pain. Wolf et al<sup>14,15</sup> used

a qualitative approach to study adult patients with chronic orofacial pain when she conducted indepth interviews with 14 patients. But to the authors' knowledge, qualitative methods have not previously been used to study adolescents with TMD pain. Thus, the aim of this study was to deepen our understanding of adolescents' experiences of living with TMD pain.

### **Materials and Methods**

The method chosen for this study, manifest and latent content analysis,<sup>16</sup> is grounded in a phenomenological perspective. Phenomenology is one of many qualitative research approaches that examines the human lived experience. There are various types of phenomenological perspectives, but what unites them is the focus and the value placed on the nature of the individual's subjective experience(s).

#### Participants

A convenience sample<sup>17</sup> of 21 adolescents aged 15 to 19 took part in the study. Nineteen were girls (between 16- and 19-years old) and two were boys (both 15 years). Mean age was 17.2 years. The participants were selected from the same population in a previous quantitative study among 587 adolescents.<sup>10</sup> They were all referred to an orofacial pain clinic for TMD pain. Selection was strategic. They were chosen consecutively with the intention of mirroring as many aspects as possible of the phenomenon under study, eg, various kinds of TMD-related, current pain problems; painful clickings and catchings; myofascial pain with different locations; and arthralgia. Both girls and boys were required as informants. Together, the adolescents reflected the various types of patients that are referred to a specialist clinic.

Inclusion criteria were (1) adolescent, defined as age 12 to 19, (2) TMD pain once a week or more, and (3) able to express thoughts and feelings verbally. The patients were examined according to the Research Diagnostic Criteria for TMD.<sup>18</sup> No one declined to participate. One girl who agreed to participate was excluded from analysis because she cancelled her appointment for the interview several times.

All participants received oral and written information. 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).

#### Preunderstanding

The first author, a TMD specialist with long clinical experience in treating adolescents with TMD pain, and the second, an experienced orofacial pain clinician and researcher, had no previous experience of qualitative research. The third author is a phenomenologist and has long experience in the field of research with qualitative methods.

#### Interviews

Data were collected in individual interviews that focused on the patients' experiences of living with TMD pain. The interviewer (first author) used a brief semistructured interview guide with a list of topics to be covered. Questions were open-ended to allow the patients to express themselves on the phenomenon.<sup>19</sup> The interviewer and the interviewee were allowed to stray from the list of topics to explore areas of interest as they arose.

All participants were asked the same opening question: "What is it like to live with pain?" They were asked to describe in detail their experiences of TMD pain and the impact of pain on their lives. Open-ended follow-up questions encouraged narration, eg, "Can you tell me more?," "Can you give me an example?," and "How did you feel?" The participants were also asked to relate positive experiences concerning pain, that is, to illuminate the phenomenon of pain in its absence. After the first three interviews, the third author reviewed the transcribed interviews and approved the interview method.

Data collection occurred twice: 13 interviews were conducted between September 2005 and September 2006 and eight between October 2007 and January 2008. In most cases, the interviews were made shortly after the initial clinical examination, but, in some cases, the adolescents had also had some treatment. The interviews took place in a separate nonclinical room in the office. The first author recorded the interviews on a digital recorder, and a clinic secretary transcribed them verbatim. The interviews averaged 22 minutes (range 9 to 36 minutes). Data files were coded and archived in the database.

#### **Data Analysis**

The interview transcriptions then underwent content analysis.<sup>20–22</sup> Manifest and latent content analysis were used to analyze the text: manifest, in that codes and subcategories are descriptive and close to the text, and latent, in that categories and theme interpret the deeper meaning mediated by the text.<sup>16</sup> Research findings should be as trustworthy as pos-

sible, and every research study must be evaluated in relation to the procedures used to generate the findings.<sup>23</sup> So, before analysis, the third author examined the data for credibility-one aspect of trustworthiness-to verify that the interviews contained meaningful data. Credibility deals with the focus of the research and, in qualitative methodology, credibility is a measure of confidence in how well data and processes of analysis address the intended focus.<sup>24</sup> The analysis was as follows: (1) A sense of the material; the first author listened to the interviews again and read through the texts to get an overall impression and sense of the material. (2) Identifying meaning units; the first author then analyzed the entire text to identify all meaning units, defined as text strings that refer to pain experiences; 1,105 meaning units were found. (3) Condensation of meaning units; in this step, the content (significance) of each meaning unit was condensed in two stages and reformulated-text was shortened by removing unnecessary words while still preserving the essence.<sup>23</sup> Also, the third author read four of the interviews. The first and third authors then discussed the condensing procedure and made revisions before the first author condensed the remaining meaning units. To examine the analysis for credibility and trustworthiness of interpretations, a medically trained researcher who was not otherwise involved in data collection or analysis read three randomly selected interviews, verified that meaning units were correctly extracted, and compared extracted and condensed meaning units. Table 1 illustrates how meaning units were gradually condensed. (4) Labeling codes; condensed meaning units were abstracted and labeled with a code. Codes for each meaning unit were formulated to describe all aspects of the content in the texts. The codes were compared based on differences and similarities. No meaning unit related to experiences of living with TMD pain was excluded. Sorting was literal: one sat at a table and physically divided the main stack of data cards, each card containing one condensed meaning unit, into smaller piles-preliminary groups of meaning. Each group represented a code. (5) Structuring the codes into a theme; the first author sorted the codes into tentative subcategories. Table 2 illustrates this process. The first author then grouped the subcategories into categories. Codes related to the categories "strategies when living with pain" and "seeking care" were lifted out for later analysis and are not included in this study. Table 3 presents the subcategories and categories that remained. The first and third authors discussed and revised these groupings by first reading and analyzing the texts independent of each other. After discussion and adjustments, a

<b>Table 1</b> Example of a Meaning Unit, a Condensed Meaning Unit in Two Steps, and a Condense	Code
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Meaning unit	Condensed meaning unit (I)	Condensed meaning unit (II)	Code
It's a dull ache, a little bit the whole time, but what bothers me or what hurts most is just before it pops before the click. (P-4)	It's a dull ache, a little bit the whole time, but it bothers me. It hurts most just before it pops, before the click. (P-4)	It's a dull ache that bothers me. It hurts most just before it pops, before the click. (P-4)	It clicked and hurt when I opened the mouth. (P-4)

P = participant

Table 2 Example of All Codes Grouped into Each Subcategory				
Code	Subcategory			
I have pain in the head.	Headache			
The headache is the worst.				
In the face and the head.				
It starts in the temples and goes down into the back of the head.				
I have had headache as long as I can remember.				
I have headache without feeling the jaws.				
I thought it was only headache.				
It clicked and hurt when I opened the mouth.	Popping, cracking, clicking, and locking			
It hurts when it clicks.				
It cracks when one is opening the mouth.				
It cracks in the jaw.				
The jaw locked and I couldn't open the mouth or eat.				
It feels awkward when it jumps.				
The jaw went slack and cracked. Then it hurt in the jaws.				
I have clickings.				
The jaw catched; that was very painful.				
It's hard to open the mouth wide. It cracks and catches.				
It clatters and crackles.				

Table 3 Subcategories, Categories, and Theme that Emerged from the Content Analysis						
Subcategory	Category	Theme				
Headache	Pain is recurrent					
Headache on wake-up						
Jaw and tooth pain						
Popping, cracking, clicking, and locking						
Constant thoughts of pain						
Tired, irritated, and down	Physical problems and daily	Adolescents with TMD live with recur- rent pain; physical problems and daily demands form a vicious circle that causes adolescents to oscillate between hope and				
Can't eat, chew, open wide, yawn, or kiss	demands form a vicious circle					
Knuckle down to cope with school-related demands and stress						
Hopes to become pain-free	Mood oscillates between hope and despondency	despondency				
Hopes that the treatment will ease the pain	despondency					
Hopes to be able to do normal things again						
Feelings of disappointment and panic that nothing will change						
Accepting and getting used to the pain						

consensus was reached. The underlying meaning the latent content—of these categories was then formulated into a theme (Table 3).

## Results

The overall theme that emerged from content analysis of the interviews was "Adolescents with TMD live in recurrent pain; physical problems and daily demands of everyday life form a vicious circle that causes adolescents to oscillate between hope and despondency" (Table 3). Three categories emerged: (1) pain is recurrent, (2) physical problems and daily demands form a vicious circle, and (3) mood oscillates between hope and despondency. Although the condensed meaning units in the categories varied depending on participant, all meaning units in a category had common features. No meaning unit was found that did not fit into one of the three categories.

In the following description, each of the three categories with their subcategories is discussed. Interview quotations that typify the subcategory or category were chosen to illustrate the category's meaning.

#### Pain is Recurrent

The participants (P) expressed a pain in the head, face, jaws, or jaw joints that was more or less always present. Five subcategories representing different aspects of the recurrent pain were identified.

*The Headache Subcategory.* Headache is one of the pains that affect these adolescents. A deeper understanding of how the phenomenon appears emerged when the interviewees described the nature of their headache:

A mixed feeling of shooting pains and cramps in my teeth in my upper jaw. Then it moves higher up into my head and I get a tension headache. It feels like a migraine and then goes down the back of my neck. (P-7)

My shoulders and the back of my neck are tensed up. The headache goes from the front down into the back of my neck. It feels like everything is one big painful point. (P-12)

Not being able to take part in social life is tough. Instead of spending time with friends, some adolescents stayed home, more or less going to bed because of headache and pain: On the days I'm in pain, I feel that I can't do certain things. I can't cope with being with my friends because I have a headache. (P-12)

*The Headache on Wake-Up Subcategory.* Some interviewees described daily pain that was constant, and some described pain that fluctuated. Most woke up with a headache.

I wake up in the morning and feel that I've been clenching hard during the night and so I have a headache. My whole jaw is tired, because I've been clenching so hard. (P-9)

I wake up with it, and then it passes. Then, in the middle of the day, it comes back, and then later, sometimes, I don't feel it at all. (P-18)

Although it was common to wake up with a headache, it could also occur later in the day:

I usually have a headache in the afternoons. Not so much in the mornings. (P-13)

The Jaw and Tooth Pain Subcategory. TMD pain can be felt in the jaws and teeth. The physical origin of the pain and where it went or stayed was often described in detail, as were feelings connected to pain itself, like tension, cramps, and feelings of discomfort:

If I lay on my side and my jaws get crooked, it's painful. (P-20)

It starts in my jaw and then it can go up to my temples or down to my lower jaw. Irritating, awk-ward pain. (P-20)

The Popping, Cracking, Clicking, and Locking Subcategory. Feelings of discomfort and disability associated with jaw joints were also described in detail and were expressed as a great problem, especially when it was also painful. The adolescents used words like pops, cracks, clicks, and locks:

I've had pain for about a year now, and it started with my jaw going slack or cracking. Then it got worse and hurt more—I got pain all over my jaws and I got headaches. (P-10)

It aches just before you feel it's going to pop and then when it pops until it clicks. First it aches and you think, it's going to happen soon, then it pops and then it clicks. (P-8) The Constant Thoughts of Pain Subcategory. TMD pain occupied the minds of the adolescents, and they thought about it constantly, even when it was absent:

I didn't used to think about it much; I was used to having it. But now I think about it all the time, whether or not I'm in pain. (P-13)

I don't have time to think about if I'm in pain. If I do, I'm in pain. It's there if I think about it. (P-6)

One 17-year old girl with catchings, lockings, and severe pain in her jaw joints had thought a lot about the problem and why it affected her so much. Her TMD pain had, in a sense, taken over her life, and she could hardly go to school:

I can't shut it out. It's too near my brain. (P-2)

Findings under this category are similar to what was expressed in a study among adolescents with chronic pain by Carter et al<sup>25</sup> using a qualitative method.

# Physical Problems and Daily Demands Form a Vicious Circle

The adolescents described being tired and moody. When in pain, they had difficulties concentrating in school or they stayed home from school. School work was affected. Adolescents also described demands and stress that seemed to be mostly related to school. Stress made them tense, and tension gave them pain. Three subcategories were identified.

*The Tired, Irritated, and Down Subcategory.* The more or less constant pain put the adolescents in a bad mood:

I used to be a happier person. Now, I'm easily irritated. In the past, if something at school seemed a bit boring, I just stuck with it. I just don't have the energy now. (P-8)

Pain puts me in a bad mood and makes me irritable and I take it out on those around me. (P-4)

It affects me negatively. I'm not very attentive and don't keep up like I should at school. I get a little more irritated with people if I am tired and have pain. (P-18)

The Can't Eat, Chew, Open Wide, Yawn, or Kiss Subcategory. Other consequences were more functional. Very concretely, jaw function was affected, and in combination with pain, this could cause difficulties. Examples are the previously described catchings and lockings in the jaw joints. Several interviewees described eating problems. Eating food is important, and some individuals reported huge difficulties when eating; they experienced painful catchings and sometimes lockings in the jaw joints:

It's tiresome when you can't eat all kinds of food. If I'm stressed, I can't eat fast, can't chew big mouthfuls, and everything takes so much longer. (P-20)

It is also embarrassing when your jaw joints click and people stare at you. One girl had such problems eating with other people that she chose not to eat at school (in Sweden, a lunch is served for free in school); she went home for lunch every day:

If you eat something where you don't have to strain your jaw, then it's not that bad. It's when you have to open your mouth wide and it cracks and your jaw locks that it's awkward and tiresome. It catches, and you can't close your mouth, so then you have to push it. (P-8)

More intimate or private consequences are rarely talked about in the clinic. This was revealed in one of the interviews:

We can't cuddle in a normal way, and if we want to fool around or hug each other, I can't because of the back of my neck. Kissing is impossible. I can't because of my jaw. So we just give each other small pecks. (P-4)

The Knuckle Down to Cope With School-Related Demands and Stress Subcategory. Vicious circles with demands and stress, especially those related to school, generate tension, and one has to knuckle down to cope with all the demands and stress at school.

I've been at home because I had a bit of fall depression. It means you miss school, and when you get back, you're behind. You don't have the energy to catch up, you already feel bad....It becomes a vicious cycle. (P-7)

One girl described how she literally clenches her teeth:

When I concentrate, study, when I play the drums or when I'm angry, annoyed, and sad, I clench my teeth. Sometimes when I'm happy, my whole body gets tense. Strong emotions make me clench my teeth. (P-12) One pain consequence could be school absence:

Some mornings the pain is terrible, so I haven't the energy to get up and I miss the first hour of school. When that happens, I tell my teachers I had a headache. But they don't know I have jaw problems. (P-9)

Meldrum at al<sup>26</sup> also found that pain affects mood and makes adolescents feel anger, sadness, worry, fear, and frustration. The same authors found that functional limitations were a predominant theme among children with chronic pain, causing frustration and distress.<sup>27</sup> Söderberg et al<sup>28</sup> found women with fibromyalgia describing, in similar ways, how pain invading the body caused anger and irritation.

# Mood Oscillates Between Hope and Despondency

Being young and already facing persistent pain problems is difficult. Many of these adolescents had had pain for months, sometimes years. The pain affected the adolescents' lives and, emotionally, the adolescents oscillated between despondency and feelings of hope and belief in recovery—from feeling that recovery from pain might be possible with proper treatment to despairing of ever being pain-free. This category comprised five subcategories.

The Hopes to Become Pain-Free Subcategory.

I never expect to feel 100% well. If I just get rid of some of it, life will be better. (P-4)

I hope I'll get rid of some of my headache. I don't think I'll get rid of it all, but maybe things will be easier. My jaws and my head more relaxed. (P-18)

The Hopes That Treatment Will Ease the Pain Subcategory. Some had heard about others who have been treated and cured:

I don't have any high hopes, but I hope that not biting so hard anymore will make it better. I can still get a headache, but I don't have it as long and it's not as bad. I don't think I'll get rid of everything. (P-7)

I hope it'll get better. A girl in my class, her mother has a splint, and she got much better. I hope it will be the same for me. (P-3)

The Hopes to be Able to do Normal Things Again Subcategory. Restrictions and disability in function and daily living gave rise to hopes that, one day, they would be able to do what they used to do. When things are normal, like a jaw should be. That you can do things that you're supposed to be able to do. Things I could do three years ago. (P-20)

The Feelings of Disappointment and Panic That Nothing Will Change Subcategory. When the adolescents experienced frustration, they had no management strategy and could not find a way out of it. Some of them had nearly lost hope, and they felt disappointment and panic that it would always be like this:

When I found out that I couldn't get rid of it completely, that I couldn't be completely well, I panicked even more, thinking I wouldn't be able to eat. (P-2)

I think it's tiresome, because your jaws are there the whole time. Tiresome to have this for the rest of your life. (P-5)

All the doctors say I've got a low pain threshold, that I have to train it up and that I'll have to learn to live with it, but it's not so easy. (P-4)

The Accepting and Getting Used to the Pain Subcategory. The adolescents accepted or internalized their pain. They felt that pain had become an immovable fixture of life and that there was nothing they could do about it:

I notice it when I wake up, then I don't notice it during the day because it's the same ol' damn pain. When I don't think about it, I don't feel it. (P-12)

Unfortunately, you get used to the pain. You forget what it feels like to be able to open your mouth wide and eat normally. (P-2)

Findings under this category expressing hope and despondency correlate with findings in studies among adults with fibromyalgia<sup>28,29</sup> and adolescents with chronic pain.<sup>25,26,30</sup>

## Discussion

This study demonstrates how to acquire a deeper understanding of the phenomenon of living with TMD pain. Patients were considered on a patient level not on a group level—to achieve a more profound understanding of the unique, individual patient.

Content analysis, a common, validated qualitative method, often used in nursing research,<sup>20,23</sup> revealed

through the adolescents' interviews how living with TMD pain involves, more or less, constant suffering for the individual in that the adolescents were either experiencing pain or thinking about it. The adolescents expressed that TMD pain had a marked effect in many areas of their lives. Everyday activities such as eating and talking, as well as their social and emotional lives, could all be affected. Schoolwork could suffer when they had to stay home because of pain. Many described tiredness, dropping out of doing things, and not being with friends. They were also worried about the future and questioned whether they would ever be pain-free. All these findings are identical to the findings of Meldrum et al<sup>27</sup> in a study using semistructured interviews among adolescents with chronic pain. Hunfeld et al<sup>31</sup> had similar findings after interviewing adolescents with persistent pain. Pain spilling over into every aspect of life was also found by Castle et al<sup>32</sup> in a phenomenological study among adolescents with chronic pain and cerebral palsy.

Adolescence is generally a stressful time of life, with increasing cognitive, physical, and social demands. Having pain makes these all the more challenging.<sup>33</sup> Persistent pain is a constant reminder to sufferers that their bodies are there and something is wrong; in many cases, daily activities are impaired.

The interviewees all described typical TMD characteristics, such as pain, reduced jaw movements, or joint sounds. The transcribed interviews contained detailed descriptions of TMD pain location, quality, frequency, duration, and intensity. Headache has been studied extensively, also with qualitative methods.<sup>34</sup> In the present study, many of the adolescents described having headache as well as TMD pain. Previous research has described how TMD pain has a considerable impact on adolescents.<sup>3,5,6,9,10,35</sup> The present study demonstrates that pain varies from individual to individual and that the pain sufferer has a constant awareness of pain, thinking about the pain even when it is not there.

Another category was "physical problems and daily demands form a vicious circle." Pain affects mood, and one of the three subcategories was the "tired, irritated, and down" subcategory. Similar findings occurred in the study by Meldrum et al,<sup>27</sup> who identified differing emotions among adolescents with chronic pain, such as anger, depression, sadness, fatigue, and frustration. Among adult chronic pain sufferers, Sofaer et al<sup>36</sup> found tension, worry, and irritability commonly occurring. Lowered mood and depression can be contributing factors to pain,<sup>37</sup> and studies have shown that heightened levels of psychological distress can be a consequence of pain.<sup>38</sup>

Outcomes in the earlier quantitative study<sup>10</sup> are described in terms of jaw function limitation, depressive symptoms, somatic complaints, and graded chronic pain severity (GCPS). The GCPS questionnaire assesses the psychosocial functioning of the patient and is an indicator of the extent to which the TMD pain is psychosocially disabling.<sup>39</sup> In the present study, 12 adolescents had a GCPS with a lower grade of disability, eight presented with high disability and moderate limitation, and one with severe limitation. As expected, the adolescents with the higher GCPS grades of disability and limitation described the more severe complaints in the interviews. Wolf et al<sup>15</sup> used quantitative and qualitative methods to study adults with chronic orofacial pain and concluded that there is a value in using both methods because the GCPS questionnaire does not clarify how the pain influences the patient. Qualitative methods capture aspects of a patient's pain picture that are not measurable quantitatively, and that could alter treatment planning.

The vast majority of adolescents with TMD pain problems are girls.<sup>4</sup> Girls also scored higher than boys on most variables (eg, a perceived need for treatment) measured in the study with quantitative methods.<sup>10</sup> These findings might indicate that girls suffer more than boys. This would help explain why girls seek more care<sup>9</sup> and why the majority of patients in this study were girls.

Worries about the future, expressed by the adolescents in the "feelings of disappointment and panic that nothing will change" subcategory, were also found by Meldrum et al<sup>26</sup> among adolescents with chronic pain.

Hope can be a desire of relief from something ongoing. Hope can also be the rejection of depressing thoughts, imagining that tomorrow will be better.<sup>40</sup> Feeling hope is a prerequisite for humans to experience health, as hope is irrefutably linked to a person's imagination about a happy future. Two subcategories, "hopes to become pain-free" and "hopes that treatment will ease the pain," are in line with what was found in the Carson and Mitchell study,<sup>41</sup> with qualitative methods, on adults with persistent pain. Carson and Mitchell's participants described hopes related to comfort and relief and spoke of ways to continue. The present findings correlate with findings in another study<sup>33</sup> with qualitative methods among children and adolescents with juvenile idiopathic arthritis (JIA), where the adolescents described their lives as oscillating between despair (shaped by pain, limitations, dependency, worry, and fear) and hope (a belief in recovery).

Twenty-one adolescents were interviewed in the present investigation. Studies using qualitative

methods tend to have small sample sizes and abundant descriptive data. In general, the adolescents were fairly difficult to interview. Some adolescents seemed unused to talking about their situation in this way. It was sometimes difficult to get them to talk openly, despite use of open-ended questions; while the interviewer was a professional, they were teenagers, with feelings of uncertainty or shyness that are sometimes characteristic for that age range. Another reason could be that communicating pain is difficult, a finding made by Dudgeon et al<sup>42</sup> among adults with physical disability and pain and by Carter et al<sup>25</sup> among adolescents with chronic pain.

The method, comprising continuous group discussions of the various phases of the study, supports study credibility and trustworthiness. The method recommended for achieving trustworthiness for the generation of category systems,<sup>23</sup> and which was used here, involves the researcher independently generating the lists of categories and a colleague who did not participate in the study checking the credibility of the analysis process.

The issue of interviewer influence on data is important. The interview guide contained open-ended and follow-up questions, and informants were encouraged to narrate freely and in detail. The interviewer tried not to steer the adolescents, merely guide them at points. Depth in data is important. For example, if the interview is too short or superficial, and the data are too shallow, latent content analysis, and identification of a theme, is difficult.

Meanings and use of validity and reliability in the field of qualitative analysis differ somewhat from those in quantitative analysis. In qualitative work, validity (trustworthiness) refers to confidence in how well data and processes of analysis address the intended focus (credibility), and reliability to the degree to which (1) data change over time and (2) alterations are made in the researcher's decisions during the analysis process (dependability).<sup>23</sup> The first interviews that were made were checked for credibility concerning data quality, which contributed to interview quality. The same researcher conducted all interviews and used the same semistructured interview protocol, thus dependability can be considered high. The method design, which requires other researchers to examine the data (meaning units) and verify the analysis, makes the process trustworthy. Validation, or trustworthiness, could have been improved by asking the informants to confirm the theme and, thus, the interpretation and analysis.

The interviews revealed the extent of the difficulties caused by functional pain in the jaws and jaw joints and on quality of life caused by recurrent pain. The theme that emerged in this study contains new knowledge that would have been impossible to obtain via questionnaire instruments. Pain and suffering are not synonymous. Even though an outsider can never fully judge another person's pain experience, this study demonstrates that deeper knowledge of the pain experience and how it contributes to a person's suffering is possible.

Pain is a private experience that only one person has access to—the sufferer.<sup>42</sup> This study demonstrates that a better understanding of this experience by outsiders is possible. Because pain is invisible, listening is important since it is the only way to understand a patient's suffering. A more holistic understanding of patients' pain experiences would increase our possibilities to support and treat the adolescents in a more individualized way.

### Conclusions

Adolescents who live with recurrent TMD pain are living with a pain that has a substantial impact on their lives. Even in pain-free periods, the adolescents appear to be thinking about their pain. This study's findings describe interactions between various aspects of pain. Physical problems interact with daily demands. This vicious circle causes adolescents to oscillate between hope and despondency.

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