

Nonspecific Chronic Orofacial Pain: Studying Patient Experiences and Perspectives with a Qualitative Approach

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Aims: To analyze the nonspecific chronic orofacial pain patient's experience of the pain condition and to gain knowledge on the complexity of the problem. **Methods:** Fourteen patients (11 female, 3 male) aged 21 to 77 years were selected among those referred to a specialist clinic. All selected patients agreed to participate. Data were obtained through thematic in-depth interviews that exposed the context of the orofacial pain condition. The 2 interviews with each patient were audiotaped and transcribed verbatim. The text material was analyzed using a qualitative research strategy based on phenomenology. **Results:** The essence of the chronic orofacial pain was expressed by the patients as something that eludes perception and comprehension. The pain was difficult to grasp and to communicate. The consequence of the pain was experienced by the patients as to be stricken by the pain and was expressed as living a life permeated by hopelessness, resignation, and a lack of faith. **Conclusion:** The patients in this study experienced their chronic orofacial pain to have no limits and to repressively permeate all aspects of their existence: social, practical, and emotional. J OROFAC PAIN 2008;22:349–358

Key words: chronic pain, facial pain, pain consequence, patient perspective, qualitative research

Recent studies indicate that many chronic pain patients still experience pain several years after treatment. They suffer, seek care repeatedly, and often receive a wide range of treatments, which leads to an economic burden on themselves and society.^{1–7}

Chronic orofacial pain and psychologic factors are reported to be interrelated.^{1,8} A common finding is that patients suffering from chronic orofacial pain have greater levels of distress than the general population.^{9,10} Even though psychologic factors seldom are the primary cause of chronic orofacial pain, physical and psychologic symptoms frequently coexist. The patient's emotional state is considered important since it affects the patient's coping abilities and treatment outcome.^{9,11–14}

In the study of chronic pain conditions, the biomedical approach focuses mainly on separate aspects of chronic pain—such as the dysfunction of the biological organism or the pathophysiology of the disease state—and primarily attempts to quantify pain. Use of various kinds of questionnaires that quantify pain

variables and variables associated with pain make it possible to obtain an idea of “how strong” the pain is; it is also possible to use quantitative criteria to evaluate the outcome of pain management. Attempts to make private experience and consequences of chronic pain a product of observable and objective findings have also been frequently made.¹⁵ Knowledge of chronic orofacial pain undoubtedly has expanded. In general, however, a quantitative research strategy fails to address the complexity of chronic pain,^{16–18} a circumstance that may be important, since chronic pain is reported to have implications for every aspect of life and to be interwoven with existential issues such as meanings of life in general.¹⁹ To retrieve knowledge on patients’ feelings and values, qualitative research methods using, for example, interviews are preferred, since the subjects can narrate their own experiences without restriction.²⁰

The experience of chronic pain involves not only a sensory component but also components of a cognitive and an affective nature, a fact that influences current holistic chronic pain treatment rationale. One prerequisite of a holistic view is the patient perspective of the condition.²¹ Studies that use a qualitative research approach to reveal the perspective of the patient have significantly improved the understanding of patients suffering from chronic pain.^{20,22} But the perspective of chronic orofacial pain patients remains largely uninvestigated. Of particular interest is the difference between the patient’s experience of illness and the clinician’s attention to disease. To meet the demand for studying the feelings and experiences of patients in their context, a qualitative research strategy has the advantage of discovering information not obtainable with other research strategies such as questionnaires. Focusing on the meaning of the orofacial pain from a patient perspective and the context in which the pain experience occurs might improve our understanding of patients’ experiences and thereby shed light on the complexity of chronic orofacial pain.

Among patients suffering from chronic pain are those in whom the cause of pain is unknown or the pain behavior appears to differ from the objective findings of the consultation. Health-care providers report that these patients cause frustration and are especially difficult to take care of^{23,24}; the authors therefore considered it important to study these patients.

The aims of this study were to analyze the non-specific chronic orofacial pain patient’s experience of the pain condition and to gain knowledge on the complexity of the problem.

Materials and Methods

Several results concerning the patients included in this study were reported earlier and dealt with the patients’ experiences at consultations.²⁵ The patients were selected from 191 chronic orofacial pain patients who were referred to the Orofacial Pain Unit at the Faculty of Odontology, Malmö University, Malmö, Sweden, from 2002 through 2004.

Inclusion criteria (IC) (Table 1) for patient participation in this study were at least 1 of the following:

- A. Lack of a reasonable explanation of the chronic orofacial pain condition.
- B. Pain behavior that, to an experienced clinician, appeared to be incongruent with the pain described.

The sample consisted of 14 patients (11 female, 3 male), aged 21 to 77 years. Twelve were Swedish, 1 was from a neighboring Scandinavian country, and 1 was from Eastern Europe (Table 1). The patients were strategically selected, according to the inclusion criteria, through a purposive sampling of patients considered to be especially difficult to understand. Eight patients were selected during clinical consultations at the Pain Unit and 6 based on case histories from previous clinical examinations. All selected patients consented to participate in the study. Seven of the patients were married, 2 widowed, and 5 single. Of the 10 patients who had children, 4 still had children living at home. Six patients were employees or self-employed, 5 were retired, 2 were sick-listed, and 1 patient was a student. Concerning educational level, 1 patient had a university degree, 6 patients had upper secondary education, and 6 a compulsory school education. Information for 1 patient was missing. Self-reported pain duration ranged from 3 months to 20 years (Table 1). Eight of the patients reported pain outside the orofacial region. Thus, the patients formed a heterogeneous group. The Research Ethics Committee, Lund University, Lund, Sweden, approved the study. A qualitative phenomenological approach was chosen and was based on principles formulated by Giorgi,²⁶ Moustakas,²⁷ and Kvale.²⁸

Data Collection

The interviewer (EW) made primary contact with the patient, either at the Orofacial Pain Unit or by telephone, and presented information about the study. After the patient consented to participate, an interview was scheduled. Each patient was

Table 1 Sex, Age, Reasons for Selection, Clinical Diagnoses, Inclusion Criteria (IC), Registrations for Graded Chronic Pain Scale Severity, the Symptom Check List-90, and Intensity of the Orofacial Pain Condition of the Nonspecific Chronic Orofacial Pain Patients

Sex	Age	Reasons for selection	Clinical diagnoses	IC	GCPS*	SCL-90 depression/somatization†	Pain intensity‡	Pain duration (y)
Female	76	Inconsistent descriptions of the location of the pain	Myofascial pain with limited opening Atypical facial pain	A, B	IV	Severe/severe	6/7	0.3
Female	40	Contradictory body language	Myofascial pain Osteoarthritis Episodic tension-type headache Atypical odontalgia Fibromyalgia	B	IV	Severe/severe	10/10	2
Female	66	Suffered much but declined further treatment	Osteoarthritis Disc displacement without reduction with limited opening Myofascial pain with limited opening	B	III	Severe/severe	10/10	9
Female	74	Extreme anger about the health care received; pain description inconsistent with clinical results	Myofascial pain with limited opening Atypical facial pain	A, B	III	Severe/severe	8/10	3.5
Female	77	Extreme fatigue from the pain	Burning mouth syndrome Lingua geographica	A, B	II	Severe/moderate	10/9	–
Male	68	Requested removal of amalgam fillings; explained the pain in a bewildering fashion	Atypical fascial pain	A	–		–	–
Female	32	Did not accept medical explanations of the pain; demanded further treatment	Atypical odontalgia	B	IV	Severe/moderate	6/10	1
Female	57	Requested removal of amalgam fillings; pharmacologic agents provided no pain relief	Atypical odontalgia Sjögren syndrome	B	IV	Severe/severe	9/10	3
Male	54	Did not complete the pain examination; preferred alternative health care	Chronic tension-type headache Myofascial pain	B	II	Moderate/severe	4/7	2
Female	37	Provocative attitude at pain examination	Myofascial pain Arthralgia Atypical fascial pain	A, B	II	Normal/moderate	1/10	20
Female	61	Requested removal of amalgam fillings	Atypical odontalgia	B	II	Normal/normal	5/7	17
Female	21	Extensive personal demands; described extreme fatigue	Myofascial pain with limited opening Arthralgia Chronic tension-type headache Cervical pain		IV	Moderate/severe	8/9	2.5
Female	69	Did not accept medical explanations of the pain; pain description inconsistent	Myofascial pain Limited opening Atypical odontalgia	B	–	Moderate/normal	5/7	0.5
Male	42	Did not accept medical explanations of the pain; demanded further, not medically acceptable treatment	Chronic tension-type headache Myofascial pain Atypical facial pain	A, B	II	Severe/severe	7/7	2

*GCPS Graded Chronic Pain Scale severity (Grade 0: No TMD pain in the prior 6 months, Grade I: low disability, low intensity pain, Grade II: low disability, high intensity pain, Grade III: high disability, moderately limiting, Grade IV: high disability, severely limiting).

†SCL-90 the Symptom Check List 90 (Depression: Normal < 0.535, Moderate .535–1.105, Severe > 1.105. Somatization: Normal < .500, Moderate 0.500 to 1.000, Severe > 1.000).

‡Present state of pain/worst pain experienced as rated on an 11-point numeric rating scale with the anchor definitions: 0 = no pain and 10 = unbearable pain. – Missing data.

Table 2 Themes Chosen to Explore the Personal Experience of Pain in Interviews with Nonspecific Chronic Orofacial Pain Patients

Themes
Interview 1
• The present state of pain
• The latest instance of pain
• Other concrete instances of pain
• The commencement of pain
• Life before the commencement of pain
• Life between instances of pain
Interview 2
• The patient's reflections following interview 1
• The interviewer's reflections following interview 1
• The future

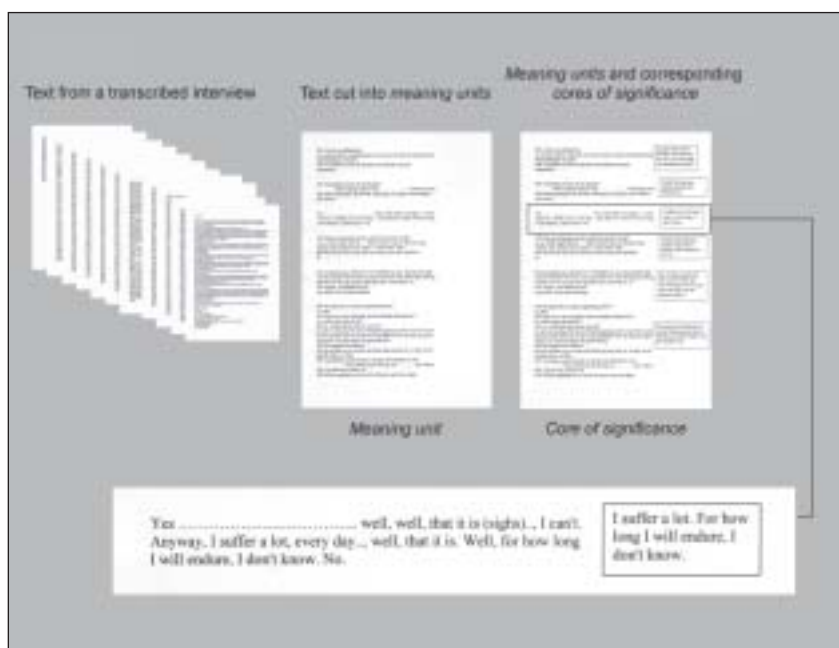


Fig 1 The text preparation process. An example of division into “meaning units” condensed into more succinct formulations, “cores of significance.” A meaning unit and a core of significance in magnification are visualized.

interviewed twice for 45 to 110 minutes, with an interval of 1 week to 4 months. The interviews were audiotaped and conducted in a nonclinical environment, either at the Faculty of Odontology or in the participant's home. The interview themes covered the context of the orofacial pain condition (Table 2). Patients were encouraged to describe their experiences in their own words, aided by the interviewer's use of open-ended questions. The interviews were conducted on 2 occasions to ensure that the interviewer and the patient had plenty of time to communicate and that both parties had an opportunity to reflect on the first interview. The patient was given a copy of the first interview to listen to in the interval before the second interview so that he or she could comment on and correct misunderstandings in the first interview.

Text Preparation Process and Analysis

For each patient, the interviewer transcribed the 2 interviews verbatim and used the following process (Fig 1) to prepare the text for analysis:

- The transcript was read in its entirety to get an overall impression of the interviews.
- Text was cut at the point a change in meaning occurred in the text; “meaning units” were identified.
- Meaning units were condensed into more succinct formulations by excluding all “unnecessary words”; “cores of significance” were identified.
- For the purpose of this article, cores of significance dealing with the patient's everyday experience of the pain condition were identified and separated for analysis. Cores of significance were selected from both interviews.

Analysis of the cores of significance focused on the patients' expressions within the statements. By analyzing not only *what* the patient talked about but especially *how* the patient spoke, the process allowed access to emotions and meanings associated with the patient's everyday experience of the pain. During analysis, various patterns in patients' experiences emerged, which exposed a variety of aspects of nonspecific chronic orofacial pain as a phenomenon. The interviews were reread to recontextualize the patterns. To make findings accessible for analysis, the emerged patterns—including variations on these patterns—were classified into categories and subcategories. The patterns and the categories were questioned, compared, and finally agreed upon by all authors. The quotations selected from the interviews to illustrate various concepts in this article were transcribed from spoken to written language and translated into English.

Information in the patient records was used to further describe the patients. This information included results of previous examinations made according to the Research Diagnostic Criteria for Temporomandibular Disorders (RDC/TMD),¹⁵ registrations of pain intensity and disability with the Graded Chronic Pain Scale (GCPS), and classification of depression and somatization with the Symptom Check List (SCL-90R). RDC/TMD, GCPS, and SCL-90R scores were added to the information collected from the interviews (Table 1).

Results

During systematic analysis of meaning in the collected data concerning the lived experience of nonspecific chronic orofacial pain, 2 main categories were identified: elusive pain and hopelessness. Each category had common features, even though each participant expressed his or her own variation.

Elusive Pain

This category describes the essence of the pain as something that eludes perception or comprehension. Two subcategories illustrating different aspects were identified:

- Pain that is all-embracing
- Pain that is difficult to communicate

Pain that is All-Embracing. The elusiveness of the pain emerged clearly in the pattern of responses where pain was described as all-embracing. Pain was perceived first and foremost, before everything else in life, and was not limited to any functional or

social areas. The pain appeared to be the dominant feeling in the narrations. One reaction to pain that is all-embracing was to ignore other problems besides the current chronic orofacial pain.

I have no other problems in my life, not a thing. No, absolutely not. I don't. The pain is my problem. Mm.

Another variation within this subcategory was a strong preoccupation with the pain, exemplified by the use of exaggerations and a superfluity of tiny details in the descriptions of the pain consequences and the reported existence of a pain diary. In the interviews, pain that is all-embracing could also be expressed physically when a patient changed how she held her body in response to the pain.

You tense muscles, you tense everything. Your entire body gets deformed in some way, in the end. [...] If you have pain, then it is as if it reproduces and spreads.

Pain that is Difficult to Communicate. Most patients found it difficult to describe their chronic pain, even though many had several years of pain experience. The patients lacked words to illustrate their pain and suffering. To communicate the pain was difficult, even on a questionnaire that contained a variety of pain descriptions.

I have terrible problems when I try to explain my pain, because when it hurts, I try not to focus on it. [...] So when I got this paper from the dentist: "Describe the pain. Is it burning or sticking?" I was completely taken aback: What??? (laughs). No idea. I can't explain.

I don't really understand. It is difficult to explain your pain. Quite simply, I have pain.

But despite the generally expressed difficulty to communicate the pain, some patients used comparisons and metaphors during the interview to describe their feeling.

The pain begins with such rapid cuts. And then another one comes. It goes over into a numbing pain, then it becomes aching and then goes over into extreme pain.

Difficult-to-communicate pain was also described as "invisible pain." Because the pain was invisible, care providers and social contacts—according to the patient—got the impression that he or she was intact and not suffering from pain.

When the pain is not visible in your behavior, it is twice as hard to be understood. I have to work twice as much, so I soon give up.

The difficulty of transferring an understanding of the pain experience to others was also expressed by 1 of 5 patients who spontaneously related a history of being the victim of sexual, physical, or psychological abuse.

I understand that it is very difficult to understand how serious this is. About as difficult as imagining a situation where a person is abused and lives in such a relationship.

Communicating the pain was further complicated by an expressed difficulty to understand what actually had happened and also by an attempt to ignore the pain to escape facing it.

If I think that it really hurts, then I change that feeling into a pain that exists. Then it has become real in my body. Then it has taken over, because it is so negative. Then I have died. Then it is hell to get out.

Hopelessness

This category describes the repressive consequences of the pain in the patients' lives. The mood of the patients was characterized by a lack of hope. Two subcategories of hopelessness were identified:

- Feelings of being stricken by the pain
- Feelings of resignation

Feelings of Being Stricken by the Pain. Feelings of being stricken by the pain emerged when the patients expressed being trapped by the pain and finding it difficult to mobilize enough strength to perform daily hygiene routines or even to get up in the morning. A great need for preparation before activities and for resting was apparent. Pain had an impact on daily life; it made it difficult to plan, it was an obstacle to being social, and the result was often passivity.

And the passivity! I should be able to go out. I am in my best years now, I think, but I have no need to follow along. The pain is simply too much.

The patients considered pain in the orofacial region to be in a class of its own compared to pain in other regions of the body. One patient com-

pared herself to other patients who suffered from chronic pain outside the orofacial region and attended the same pain treatment group.

I understand now that the pain is more a part of me than it is of the other patients in the treatment group. I am more psychologically affected. The others have more or less made friends with their pain.

Some patients described being stricken by the pain, as if the pain was like a punishment. This could be experienced in situations where the patient, for example, asserted her right and then described how the pain returned with renewed strength because of her assertive behavior. Pain as a punishment could even be expressed at an existential level.

I don't know why, but it feels as if I have been punished. It is exactly as if He is sitting up there and laughing.

Feelings of Resignation. Feelings of resignation were especially prominent when the theme "future" was discussed in the interview. In general, this theme was quickly dropped by the patients. Sometimes, the question of the future was simply ignored and the subject immediately changed. Statements about the future were generally negative and expressed a lack of faith.

There is no future for me, that much I have understood.

The patients' mode of managing the theme "future" at the interviews was similar to their management of the theme "life between instances of pain." The patients only briefly discussed pain-free periods; distractions that helped take their minds off of the pain were scarcely mentioned, although patients occasionally related pain-free moments.

Feelings of resignation were also expressed when patients described how people close to them thought their personality had become more melancholic after being afflicted with the chronic pain. Another example of behavioral change was the development of a destructive behavior because of the chronic orofacial pain.

I got epilepsy after the birth of one of my children. I found a morphine-like painkiller that people with epilepsy should not take. I thought: "I don't care. I'll just have to die, then."

Only 1 of the 14 patients deviated from the general pattern of hopelessness. Although this patient

also expressed doubtfulness about the future, he, in contrast to the others, gave the impression of being able to differentiate between the chronic orofacial pain and his entire life situation and of having developed a personal coping style with some control of the pain.

As long as the pain doesn't get any worse, I'll be able to manage it. And if I can keep it down with a little massage and other things, my time will pass (laughs).

Discussion

The analysis of the in-depth interviews improved understanding of the patients' everyday experience of the chronic orofacial pain condition as something that eludes perception and which has a repressive impact on all of life: social, practical, and emotional. It was striking that, although the patients presented a wide variety of social backgrounds, clinical features, diagnoses, and reasons for selection, the patterns that emerged from the analysis were similar. This finding indicates that what is most important for health-care providers might be to focus on the chronic pain impact on everyday life and to provide enough time at the consultation to make this possible. It also seems important to try to identify chronic pain patients where the pain or the consequences of pain are experienced as the main problem. To discriminate these patients from those for whom their chronic pain is no big problem²⁹ may help caregivers choose the most effective treatment strategies for different groups of chronic orofacial pain patients.

The method chosen to analyze the qualitative data made it possible for the narration of the patient to be heard. It was important that the personal notions and expectations of the interviewer did not intrude upon the interview itself. Because the interviewer was an experienced clinician and familiar with the interview technique, such interference was avoided. That interviews were conducted on 2 occasions was considered valuable for 2 main reasons: it ensured enough time for communication and it gave an opportunity for both parties to comment. The patients seemed more relaxed at the second interview and related experiences of great personal concern on this occasion; for example, the experience of abuse was mainly developed at the second interview. An interpretation of this was that an atmosphere of confidence between the interviewer and the patient had then been sufficiently established to allow emotionally

difficult experiences to be exposed. Unexpectedly, few patients commented on or corrected misunderstandings from the first interview.

The pattern that emerged during the interviews—and which is described in the category “elusive pain”—is of a chronic pain that seems to have no limits and to permeate all aspects of the patient's existence: social, practical, and emotional. Chronic orofacial pain does not seem to differ from other chronic pain conditions in that it has similar consequences for all aspects of a patient's life.^{16,17,19,30–34}

It is interesting that the patients had difficulties communicating the feeling and experience of their pain. One probable interpretation is that the patients felt the pain to be indefinable and all-embracing and, accordingly, difficult to communicate. This interpretation is based on the finding that the pain seems to be invisible, to be unlimited, and to embrace the entire existence of the individual. Another interpretation is that nonspecific chronic orofacial pain appears to be the predominant feeling in the stories of some of the patients and may be a cover for something worse, something that is impossible for the patient to deal with as long as the pain is allowed to hide the actual problem.³⁵

An alternative interpretation of some patients' strong focus on the pain may be that the presence of a chronic pain is a threat that creates anxiety in the patient. This will heighten attention on the chronic pain, and other stimuli will escape notice.^{29,36} A less probable interpretation of patients' difficulties to mediate the pain is that they actually lack words or the ability to express feelings. This view is less likely because although some patients said they lacked suitable words to describe their pain, they actually did use a variety of expressions concerning their pain experience. A perceived difficulty by the patient in communicating pain probably contributes to its elusiveness and its difficulty to be understood, even by the caregiver, and this was also the starting point for this study.

The clinical findings previously registered at the Orofacial Pain Unit (Table 1) were not known at the time of patient selection. But the recorded data indicate that living with the pain is in many respects difficult for these patients. The intensity of the pain reported by the patients and scores of pain disability, depression, and somatization were high, with few exceptions. The general findings were that the patients with nonspecific chronic orofacial pain selected for this study scored higher on the GCPS and the SCL-90 than a broader group of patients with chronic orofacial pain.^{8,37}

One explanation for this may be the strategic selection of patients with a pain condition that was especially difficult to understand and whose pain was most likely very complex. Questionnaires such as the GCPS and SCL-90R make it possible to determine that a patient is psychologically influenced by the chronic pain. But the essence of how the pain influences the patient still escapes the researcher. So the value of using a combination of scientific methods for quantitative and qualitative data must be underscored. The complexity of the chronic orofacial pain condition cannot be captured in questionnaires alone.

The consequences of the constant presence of the pain are characterized by hopelessness and emphasized by the few negative statements about the future and pain-free "intervals." The emotional states of the patients, which became clear after the analysis but were somewhat vague at the interviews, illustrate similarities with a state of depression, where feelings of hopelessness and a limited ability to take initiative are significant.³⁸ The pain is perceived as a prison and constitutes an obstacle to living daily life satisfactorily, since social contacts and practical everyday routines are influenced negatively; it tends to make the patient passive. This has also been previously described.³⁹ That some patients describe their pain as a punishment is another complicating factor, which implies shame and guilt, which are strongly associated with negative emotions.³⁵ These findings suggest that the psychological processes involved in nonspecific chronic orofacial pain are complicated and probably contribute to the patient's inability to manage the pain. Regardless of whether the general feeling of depression is the reason for the chronic pain or a consequence of it, it is another facet of the complexity of the chronic orofacial pain condition.

Many of the patients state that they feel especially vulnerable because the chronic pain is located in the orofacial region. Although assault and violence were not a theme of the interviews (Table 2), 5 of the patients spontaneously reported that they had been abused. The possible symbolic importance of the pain being expressed via the mouth is psychologically interesting since the mouth can be seen as a zone for sexuality and the teeth for aggression.⁴⁰ A possible connection between nonspecific pain and previous physical and mental abuse can therefore be hypothesized. Other studies have shown that individuals who have experienced abuse are overrepresented among chronic pain patients.⁴¹ Since this is another subject that is difficult to speak of and many times

avoided in the clinical context,^{42,43} it is an urgent subject for further studies. A history of abuse is something to reflect on as possibly influencing the experience of chronic orofacial pain and having an impact on the clinical situation.

This study found that nonspecific chronic orofacial pain is a biological entity *and* an emotional condition. At an existential level, pain is related to the issues of meaning and life in general. Although other interpretations of the interviews are of course possible, the text material clearly reflects that nonspecific chronic orofacial pain is a very complex condition in these patients. Treatment strategies for teaching chronic pain patients to cope with a life in pain do exist.⁴⁴ But our knowledge in this area must still be developed since it is common for patients with prolonged orofacial pain to call dentists about their symptoms, even though the pain condition of most of these patients is probably not as complex as the patients in this study. It is important for the dental field to develop constructive strategies for taking care of and meeting the needs of these patients, especially when the dental disease condition has been adequately diagnosed and treated but the patients still experience pain.

Conclusions

Findings from a qualitative study such as this one are valid only for the interviewed patients and thus cannot be used as general knowledge for patients suffering from chronic orofacial pain. To be representative of other patients with nonspecific chronic orofacial pain, new hypotheses that emanate from a qualitative study such as this must be tested for significance in other research models. Nonetheless, it is probably always important to give the patients enough time at the consultation to tell their illness story.

The main observations made in this phenomenological study of interviews with patients with nonspecific chronic orofacial pain can be summarized as follows:

- The patients experienced their pain to be all-embracing, elusive, and difficult to communicate.
- The patients felt hopeless and pessimistic about the future.
- Most patients had become stuck in the experience of their pain and lacked strategies for dealing with it.
- Previous abuse is an important theme for further studies since several of the patients spontaneously reported an experience of assault and violence.

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