

# Patients' Experiences of Consultations for Nonspecific Chronic Orofacial Pain: A Phenomenological Study

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***Aims:** To use a qualitative research study to analyze the experiences of patients with nonspecific chronic orofacial pain with respect to consultations for their pain condition. **Methods:** Fourteen patients (11 women and 3 men; age range, 21 to 77 years) were strategically selected through a purposive sampling of the chronic orofacial pain patients referred to the Orofacial Pain Unit at the Faculty of Odontology, Malmö University, Malmö, Sweden. A qualitative research strategy based on phenomenological philosophy was chosen. Thematic in-depth interviews were conducted twice with each patient in order to expose the context of the orofacial pain condition. The interviews were audiotaped and transcribed verbatim. The text material was analyzed to determine the attitude of the patients concerning their experience from the consultations. **Results:** All selected patients consented to participate. The patients expressed dissatisfaction with the consultations and related many examples of poor communication and understanding. The patients also felt a great need to be taken care of and expressed contradictory statements concerning pain improvement. **Conclusion:** The results suggest that the communication between the patients and the care providers was unsatisfactory and that the patients were limited in their ability to develop a personal coping strategy. J OROFAC PAIN 2006;20:226-233*

**Key words:** attitude, communication, consultation, orofacial pain, qualitative study

Patients suffering from chronic orofacial pain often lack a more refined diagnosis, which can result in treatment being unspecific and unnecessarily demanding on resources.<sup>1,2</sup> In line with these observations are the findings from follow-up studies that a substantial proportion of chronic orofacial pain patients still experience pain several years after treatment, indicating that diagnosis and treatment have been less than successful.<sup>1,3-7</sup>

The experience of pain is subjective and complex in character. Chronic orofacial pain has components of a sensory, affective, and cognitive nature.<sup>8,9</sup> The clinical consultation is the arena where communication about the chronic orofacial pain condition takes place. However, patients who repeatedly seek care for chronic pain report being met by an atmosphere of distrust and rejection<sup>4,10</sup> and experience medical skepticism as damaging and dispiriting.<sup>11,12</sup> The quality of the interaction between the care provider and the patient is important in subjective patient evaluations concerning both patient satisfaction and treatment outcome.<sup>13,14</sup> Thus, more knowledge of that interaction could deepen the understanding of impact of the interaction and thereby improve treatment outcome.

Within the field of dentistry, little information is available about patients' emotions and experiences of chronic orofacial pain. These phenomena have not been possible to investigate with traditional research methods. Qualitative research strategies that take into account emotional, psychological, social, and existential aspects are considered more suitable for studying pain.<sup>15</sup> A phenomenological approach highlights occurrences in life from the basis of the lived experience of the individual and allows access to the feelings and meanings expressed by the interviewees.<sup>16–20</sup>

The aim of this study was to use a qualitative research strategy to analyze the experiences of patients with nonspecific chronic orofacial pain patients with respect to consultations for their pain condition.

## Materials and Methods

The inclusion criteria for patient participation in this study were at least 1 of the following:

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

The patients who participated in this study were strategically selected, through a purposive sampling of patients according to the inclusion criteria, from the chronic orofacial pain patients referred to the orofacial pain unit at the Faculty of Odontology, Malmö University, Malmö, Sweden, from 2002 through 2004. Patients who did not meet the inclusion criteria were excluded. Fourteen patients (11 women, 3 men; age range, 21 to 77 years) were included (Table 1). Eight patients were selected at clinical consultation at the orofacial pain unit, and 6 patients were selected based on information obtained from their records. At the pain unit, the patients were examined following a standardized procedure (the Research Diagnostic Criteria for Temporomandibular Disorders<sup>21</sup>) to set diagnoses and to arrange for suitable treatment.

The first contact between the participant and the interviewer (EW) was made during a consultation at the orofacial pain unit. At this time, the interviewer took measures to foster trust by informing the patient about the study and personally scheduling appointment for the interviews, which were conducted in a nonclinical environment. The inter-

view was designed to be an interaction in which the interviewer was an instrument that allowed the patient's narrative to be told. At the interview, the interviewer took care to avoid allowing her personal notions and expectations of the interview to affect the interview. This was accomplished by the familiarity of the interviewer with the interview technique, with the kind of patients being interviewed (ie, chronic orofacial pain patients), and with the context in which the interview occurred.

The study was approved by the Research Ethics Committee, Lund University, Lund, Sweden. The participants were verbally informed about the study, and written informed consent was obtained from the patients.

## In-depth Interviews

Thematic, in-depth interviews of 45 to 110 minutes' duration were conducted twice with each patient. The themes for the interviews were chosen to expose the context of the orofacial pain condition (Table 2). The interviews focused on the patient's experience of chronic orofacial pain, and the interviewer used open-ended questions to allow the patient to freely express himself or herself on the themes. The patients were interviewed twice to ensure that there was enough time for communication between the interviewer and the patient and to provide an opportunity for both parties to reflect on the first interview. To encourage reflection, the patient was given a copy of the first interview to listen to before the second interview. The recruitment of patients ceased when certain ideas began to be repeated in the interviews and sufficient material had been collected to allow recognition of different patterns. All interviews were transcribed verbatim by the interviewer.

## Data Analysis

The qualitative phenomenological approach was based on the work of Moustakas,<sup>22</sup> Kvale,<sup>23</sup> and Giorgi.<sup>20</sup> The analysis of the text material was performed in the following way: The transcribed text from the interviews was initially read to get an overall impression of the material. The text was then divided into separate *meaning units*; the divisions between the units were placed at the point a change in meaning occurred in the text (Fig 1). The significance of each meaning unit was condensed into more succinct formulations, *cores of significance*, by excluding all "unnecessary" words, taking care to keep the meaning of the expression (Fig 2). This was done in order to make the text man-

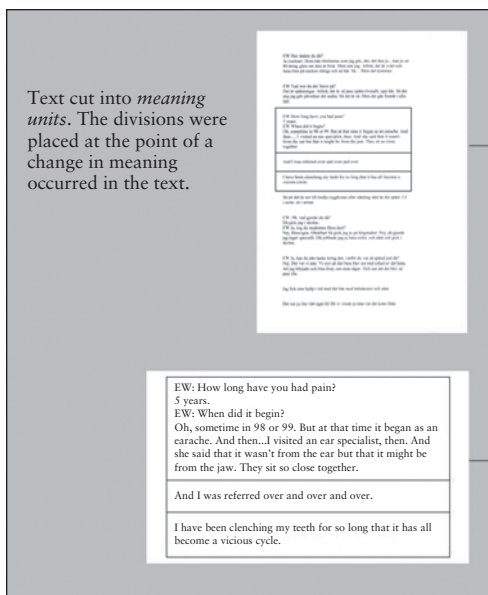
**Table 1 Sex, Age, Reasons for Inclusion, Clinical Diagnoses, Duration, and Intensity of the Orofacial Pain Condition and Occurrence of Pain Elsewhere in the Body of the Nonspecific Chronic Orofacial Pain Patients**

Sex	Age	Reasons for inclusion	Clinical diagnoses	Pain duration (y)	Pain intensity*	Body pain
F	76	Inconsistent description of the location of the pain	Myofascial pain with limited opening, atypical facial pain	0.3	6/7	Yes
F	40	Contradictory body language	Myofascial pain, osteoarthritis, episodic tension headache, atypical odontalgia, fibromyalgia	2	10/10	Yes
F	66	Suffered much but declined further treatment	Osteoarthritis, disc displacement without reduction with limited opening, myofascial pain with limited opening	9	10/10	No
F	74	Extreme anger about the health care received, pain description inconsistent with clinical results	Myofascial pain with limited opening, atypical facial pain	3.5	8/10	No
F	77	Extreme fatigue from pain	Burning mouth syndrome, lingua geographica	5	10/9	No
M	68	Requested removal of amalgam fillings, explained the pain in a bewildered fashion	Atypical facial pain	–	–	Yes
F	32	Did not accept medical explanations of the pain, demanded further treatment	Atypical odontalgia	1	6/10	No
F	57	Requested removal of amalgam fillings, pharmacologic agents provided no pain relief	Atypical odontalgia, Sjögren's syndrome	3	9/10	No
M	54	Did not complete pain examination, preferred alternative health care	Chronic tension headache, myofascial pain	2	4/7	Yes
F	37	Provocative attitude at pain examination	Myofascial pain, arthralgia, atypical facial pain	20	1/10	Yes
F	61	Requested removal of amalgam fillings	Atypical odontalgia	17	5/7	No
F	21	Extensive personal demands, described extreme fatigue	Myofascial pain with limited opening, arthralgia, chronic tension headache, cervical pain	2.5	8/9	Yes
F	69	Did not accept medical explanations of the pain, pain description inconsistent with the clinical results	Myofascial pain with limited opening, atypical odontalgia	0.5	5/7	Yes
M	42	Did not accept medical explanations of the pain, demanded treatment not medically accepted	Chronic tension headache, myofascial pain, atypical facial pain	2	7/7	Yes

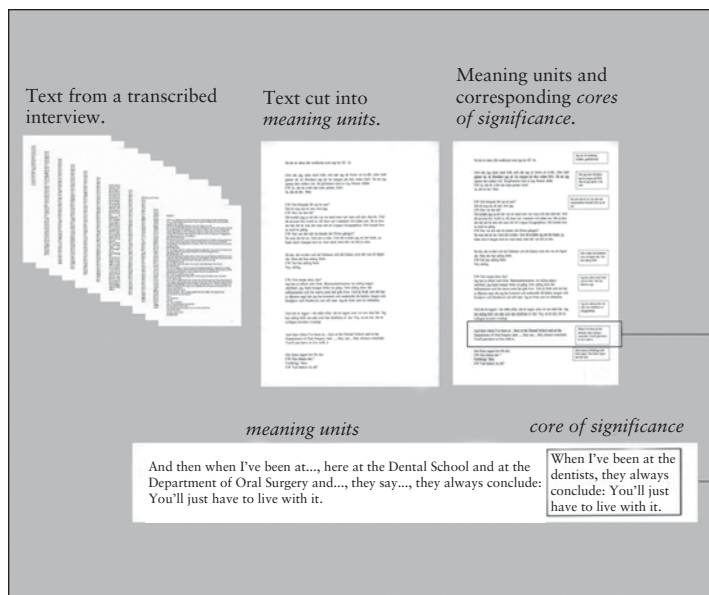
\*Present state of pain/worst pain experienced as rated on an 11-point numerical rating scale with the anchors 0 (no pain) and 10 (unbearable pain).

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

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



**Fig 1** The text preparation process. An example is shown of division of the text into meaning units. Three meaning units also are shown in magnification.



**Fig 2** The text preparation process. An example is shown of division into meaning units condensed into more succinct formulations, cores of significance. A meaning unit and a core of significance also are shown in magnification.

ageable for analysis. Information from interviews 1 and 2 was treated similarly during analysis.

A topic spontaneously brought up by all the patients and discerned in the cores of significance was the experience of the consultations about the chronic orofacial pain condition. This topic was therefore chosen for investigation. The cores of significance dealing with the consultation situations were identified and analyzed according to *who-does-what-to-whom*, which exposed the attitudes of the patients concerning their experiences of the consultations. The analysis exposed variations of the particular topic studied, which made it possible to identify patterns and classify them into categories and subcategories. All authors agreed upon the different patterns and categories that emerged. The quotations that were selected from the interviews to illustrate these categories were transcribed from spoken to written language and translated into English.

**Results**

In the systematic process of analyzing raw data on the consultation experiences of patients with nonspecific chronic orofacial pain, 2 main categories were identified: emotional vulnerability and helplessness. Although each participant expressed his or her experiences in a unique way, common features recurred.

**Emotional Vulnerability**

All participants expressed dissatisfaction with the consultations and related numerous examples of poor communication and understanding. Being in a vulnerable position at the consultation and experiencing skepticism and a lack of understanding by the care providers were commonly depicted by the patients. Four subcategories that showed different aspects of emotional vulnerability were identified: feelings of being distrusted, feelings of being insulted, feelings of being abandoned, and feelings of anger. Examples of patients' statements related to each of these subcategories are shown in italics.

**Feelings of Being Distrusted.** Throughout the interviews, the study participants generally expressed a feeling of being distrusted. It was believed that the care providers viewed what the patients said with considerable suspicion. The patients felt as if they were accused of imagining the pain. This pattern occurred, for example, when the clinician was not able to identify any objective signs that could explain the patients' symptoms.

*They take x-ray after x-ray and [snorts] find nothing. They don't believe me.*

Other occasions of distrust occurred in which the patients felt that the dentist questioned the severity of the pain or the authenticity of the patients' symptoms. One patient stated:

*It is exactly as if the dentist had said: "You're only 21 years old. You don't know how it is; you are only making it up."*

**Feelings of Being Insulted.** Another subcategory of emotional vulnerability was feelings of being insulted by the clinician. Especially prominent was the experience of not being taken seriously and instead being viewed as a "psychiatric case" by the clinician.

*I was badly treated at the clinic. The dentists who work there thought I was a "psych" case and that I needed something. They said: "There is nothing wrong with you, it is all in your head. Just calm down and get some psychiatric help instead." It isn't fun to hear such things.*

Other examples of being insulted concerned the clinicians' use of time. Patients described being left in the waiting room when the dentist was late and not being informed of the reason. Other consultations may have been cut short despite the fact that several aspects remained to be discussed.

*I feel as if the dentist is only concerned about making money. He plows through each patient, me in any case, in 15 minutes.*

Because it is vital to the patients to be perceived as credible, they felt insulted when they perceived scorn on the part of the care provider. This is exemplified by the following quotation from a patient who visited the emergency clinic at the hospital.

*Then the doctor said to me: "Go home now and rest and don't drink any alcohol."  
"I promise not to drink any alcohol, do I look as if I would want to?" I said to him. . . . I just got madder and madder as he stood there and looked at me scornfully.*

**Feelings of Being Abandoned.** The third subcategory of emotional vulnerability was the feelings of being abandoned by the clinician. Feelings of this kind surfaced when the patient was convinced of the need for further appointments but was refused any. *The dentist didn't want more to do with me. Just as if I wasn't a real person.*

Feelings of being abandoned and ignored were also expressed when the patient felt that he or she had not been thoroughly examined, when a

promised telephone call didn't take place, or when the clinician didn't remember what had been discussed at previous appointments. Situations where the patient had undergone a number of examinations and interventions and then been told that no further help could be received certainly fell within this category.

**Feelings of Anger.** A fourth subcategory of emotional vulnerability was expressed by aggression. Some patients showed their vulnerable position by becoming argumentative, demanding, and angry.

*The dentist also thought it was nice to include my private life in his analysis. He said: "You have such personal problems. You must understand that you are under pressure." Such statements make me crazy. Don't sit there and tell me what problems I have! I'll take care of that best myself!*

The interviews also disclosed that feelings of being distrusted, insulted, and abandoned, as well as feelings of anger, occurred when the patients had medical consultations for other conditions, such as back pain, knee injuries, or fibromyalgia.

There were also a few reports of satisfying consultations. When they occurred, it was in the presence of a supportive care provider who had set aside enough time for the consultations, listened to the patient with interest, and infused a feeling of being understood, which confirmed the pattern of emotional vulnerability.

### **Helplessness**

Other findings concerning the experience of consultations could be categorized as helplessness. This category captured the experience of being in great need of help and the occurrence of contradictory expressions concerning a possible future improvement. Two subcategories were identified: A great need to be taken care of and contradictory expressions concerning pain improvement.

**A Great Need to Be Taken Care Of.** One variation of helplessness was an expressed demand to be taken care of by the care providers. For instance, the patients expressed a wish for more attention than they had received from the care provider or made a definite demand to be cured. Having an expert who could instruct them in what they could or could not do was viewed as highly beneficial, and the care provider was considered to be the one best qualified to make decisions for the patient.

*I feel like I feel it now. The people at the pain clinic just have to help me find a hobby. They are going to do it now. . . . I have to have something else than home. The doctors and experts say I have to change my surroundings.*

Another example was when the patient didn't consider himself or herself to be capable to take personal action toward recovery.

*I can't do anything. . . . If the doctors can't tell me what I should do, then what should I do?*

Helplessness also took the form of laying blame on the dental profession when the patient considered the treatment to be a failure and describing the dentist as clinically incompetent.

**Contradictory Expressions Concerning Pain Improvement.** Another variation of helplessness was contradictory expressions regarding future improvement in pain. One example was when a patient talked about treatment failures during the interview, and on the same occasion, expressed a desire to undergo the same treatment again. Or, even though patients desired a future situation that was pain free, this wish was pronounced with uncertainty, and some fear was expressed when a possibility of recovery was mentioned. This feature is exemplified by a patient who was a member of a group of chronic pain patients administered by a pain clinic.

*I am happy about what I have learned in the pain group. But I'll have to see what happens. . . . I have high hopes of getting something useful from the pain group, but I don't have the energy. I've become scared, anxious.*

One deviation from the general pattern of helplessness also occurred. One of the 14 patients, like the others, perceived himself as distrusted and met with skepticism by care providers; however, he was on the contrary undemanding and gave the impression of having reached some state of acceptance of the orofacial pain condition.

*It is like I say. If it doesn't get worse, I'll manage. If it ever gets to be a lot of pain at any time, I'll just have to go lie down. There isn't much to be done. I have also said this to the others at work.*

## Discussion

The collected material gave the authors a chance to improve their understanding of patients' experience of consultations for nonspecific chronic orofacial pain. The study exposed the patients' emotional vulnerability, expressed as feelings of being distrusted, insulted, and abandoned, as well as feelings of anger. The patients also had feelings of helplessness, which were expressed as a great need to be taken care of and contradictory expressions concerning pain improvement. Conducting 2 interviews with each patient was considered valuable because it gave the interviewer the opportunity to ask the patients to explain anything that was unclear in the first interview. The patients were generally more relaxed at the second interview and related experiences of great personal concern. However, few patients discussed their reactions to the first interview. Johansson et al suggested that the transcripts should be read by the patients.<sup>4</sup> However, it is uncertain whether the variation used in the present investigation, allowing patients the opportunity to listen to the interview, is significantly different.

The findings in the category emotional vulnerability revealed that all 14 patients with nonspecific chronic orofacial pain experienced dissatisfaction with the care-taking process. This suggests that communication between the patient and the dentist as well as other care providers was unsatisfactory. The quality of the interaction between the patient and the care provider is important in subjective patient evaluations of patient satisfaction and treatment outcome.<sup>13,14</sup> Prior studies emphasize how not being believed or taken seriously affects one's honor, individual integrity, and human dignity.<sup>24</sup>

The other main category, helplessness, covered not only the patients' expressed need for being taken care of by the clinician but also the patients' contradictory expressions about pain improvement. The demands to be cured and the desire for recovery were explicitly stated and easily understandable. However, the contradictory expressions about pain improvement were implicitly expressed and obvious only after a deeper analysis of the text. This demonstrates the complexity of nonspecific chronic orofacial pain. The findings of emotional vulnerability as well as an expressed need to be taken care of at consultations regarding chronic orofacial pain conditions were in accordance with prior findings concerning chronic pain.<sup>4,10-12,25,26</sup>

The findings in the 2 main categories, emotional vulnerability and helplessness, suggested a possible inefficacy among the patients to take personal

action toward adequate pain coping or recovery. The patient's experience of the clinician's unsympathetic behavior might provide an excuse for the patient to focus on the clinician's supposed incompetence instead of the patient's own incapability. By attributing blame to the dental profession, the patient can avoid taking personal action. This was also suggested by May et al.<sup>11</sup> Further, the patients expressed a great need to be taken care of by the care providers. This attitude, together with the expressed contradictions about pain improvement, is likely to have a negative impact on the coping capacity of the patients.

Only 1 of the 14 patients in this study seemed to have reached a state of acceptance of his condition and to have developed an adequate personal coping style. The process of reinterpreting reality until acceptance of a chronic illness has been reached is described in the literature.<sup>27</sup> The patients' limited coping capacity, temporary or not, might be a matter of reflection for care providers, since its impact on treatment outcome is considerable.

Another matter of interest was whether the pattern of nonconstructive consultations characterized by negative feelings was maintained on the part of the patient as well as the dentist. The clinical consultation is the arena for exchange between the clinician and the chronic orofacial pain patient, and the patients in this study generally expressed dissatisfaction with the care that they received. The patients' narrations concerning the care they received, however, were told only from the point of view of the patients themselves and may have reflected an attempt to maintain self-respect. Irrespective of what conclusion might be drawn from an objective evaluation of the consultation, the patient's personal experience has direct consequences for the patient's well-being and is subsequently a matter of consideration for the care provider.

A significant association has been reported between the physician's rating of treatment difficulty and the patient's dissatisfaction with care.<sup>24</sup> When a diagnosis that reasonably explains the condition is impossible to make, the professional identity of the care provider is reported to be challenged, weakened, and at risk.<sup>25</sup> This might cause the care provider to attempt to protect his or her professional identity by attributing blame to the problematic patient to avoid personal responsibility.<sup>28</sup> This could partially explain the dissatisfaction with the consultations experienced by the patients in this study.

The impetus to perform this study was the difficulty in understanding patients with nonspecific chronic orofacial pain. A comparable difficulty has

been reported among care providers of some patients who suffer from chronic pain outside the orofacial region.<sup>24,29</sup> In this study a concealed message was found in the narrations about pain improvement. The implicit expressed message was contradictory to the explicit expressed demand among the patients to be cured. Although additional and also alternative interpretations of the interviews are possible, this contradictory finding demonstrates the complexity of the nonspecific chronic orofacial pain condition and might explain to some degree why these patients can be considered difficult to understand.

## Conclusions

- The patients were limited in their ability to develop a personal coping strategy. This limitation was coupled with a great need to be taken care of.
- Contradictory statements by the patients about pain improvement may have led to communication difficulties.
- Both the patients and their clinicians contributed to the maintenance of a consultation pattern characterized by negative feelings and used psychological defense mechanisms to protect personal identities.

The use of these statements as hypotheses in other research models may verify the observations made in the present study and might in such cases be representative for other nonspecific chronic orofacial pain patients.

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