

Beliefs and Distress About Orofacial Pain: Patient Journey Through a Specialist Pain Consultation

Christine J. Bonathan, BSc, DClinPsy

Clinical Psychologist
Pain Management Service
Royal Free Hospital
London, United Kingdom

Joanna M. Zakrzewska, MD, FDSRCS, FFDRCSI, FPPMRCA

Professor
Facial Pain Unit
Division of Diagnostic, Surgical and
Medical Sciences
Eastman Dental Hospital
UCLH NHS Foundation Trust
London, United Kingdom

Jenna Love, BSc, MSc, DClinPsy

Clinical Psychologist
Facial Pain Unit
Division of Diagnostic, Surgical and
Medical Sciences
Eastman Dental Hospital
UCLH NHS Foundation Trust
London, United Kingdom

Amanda C. de C. Williams, BSc, MSc, PhD, CPsychol

Reader in Clinical Health Psychology
Research Department of Clinical,
Educational and Health Psychology
University College London
London, United Kingdom

Correspondence to:

Dr Christine J. Bonathan
Pain Management Service
12th floor, North Wing
Royal Free Hospital
Pond Street
London NW3 2QG
United Kingdom
Email: christine.bonathan@nhs.net

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Aims: To explore patients' understanding of their orofacial pain, as this is an under-researched area despite emerging as a common aim of consultation.

Methods: Twelve people with chronic orofacial pain were interviewed shortly before their first consultation at a specialist facial pain clinic about their understanding of their pain, and they completed self-report measures of distress and pain interference. A day after the consultation, they wrote a short letter about how they now understood their pain and were then interviewed by phone. All accounts were analyzed using thematic analysis. **Results:** Four themes emerged across preconsultation and postconsultation data: the need for information to counteract helplessness; worry as part of making sense of pain; validation of the pain experience (all predominant preconsultation); and the importance of trust (reflecting changes in understanding since consultation). Most patients changed their understanding of pain and resolved their worries to some extent, and they reported reduced distress and less interference. **Conclusion:** Patients' fears and beliefs about chronic orofacial pain are dominated by worrying and searching for meaning before consultation. Information about their chronic pain condition counters feelings of helplessness and supports sense-making around pain when explanations are clear, are delivered sensitively from a trusted source, and take into account the patient's existing health beliefs; this promotes self-management. These findings underline the important functions of specialist consultation in achieving a shared accurate understanding of pain and options for treatment. *J Oral Facial Pain Headache 2014;28:223–232. doi: 10.11607/ofph.1184*

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Chronic pain is highly complex, with multiple explanatory models of pain used by lay and professional people,¹ so it is not surprising that some people have difficulty understanding the cause of their pain, which generates confusion and anxiety.² The way patients understand their pain partly determines their emotional reaction to it, their health-related behaviors, their overall functioning,³ and the extent to which they resolve the problem of living with pain.⁴

The belief that pain intensity is proportional to tissue damage, and that improvement is predicated on abolishing pain, traps people with pain in the pursuit of a cure that rarely exists.⁵ This is often associated with protective, ultimately unhelpful, behaviors such as guarding and prolonged resting, which can worsen disability.⁶ Additionally, a catastrophic bias in thinking has repeatedly been associated with higher levels of perceived pain, disability, and emotional distress.⁷ On the other hand, individuals who frame their problem in terms of living a more fulfilling life despite pain can find ways to reformulate and solve problems. Ideally, consultation involves an exchange of ideas,⁸ and explanations are most effective when they are plausible, blame-free, and evidence-based; address the patient's concerns; avoid contradicting previous health information; and are action-oriented and motivating.⁹

Orofacial pain is common,¹⁰ and when pain does not resolve, with or without treatment, patients seek care from both physicians and dentists, who vary in their understanding of orofacial pain.^{11,12} As in other chronic pain, patients often experience high levels of psychological distress and physical disability.¹³

Chronic or persistent pain is often associated with significant levels of distress and disability and high usage of healthcare services.¹⁴ A study of patients in specialist treatment for temporomandibular disorders (TMD)¹⁵ found that half had difficulty eating and a third had sleep problems and depression. Because the face is central to eating, communicating, and other essential functions, orofacial pain can have particular impact on these functions.¹⁶ There is only one study of orofacial pain patients' experiences¹⁷; it provides vivid descriptions of the ways in which participants feel that their pain is different. Other qualitative studies of people's understanding of their chronic pain at the point of seeking treatment, or reflecting on it, are based on mixed samples (including orofacial pain^{18,19} or low back pain²⁰⁻²²). Beyond the understandable wish for pain relief, patients expected and hoped to get a diagnosis and/or explanation, expressed in language they could understand; to feel listened to, understood, and have their pain legitimized; and to be offered information on self-management.

Quality of life can be substantially improved by explanations that help make sense of pain, its nature, and any treatment options,^{19,23} even when the explanation is complex.²⁴⁻²⁷ Treatment satisfaction of patients with various chronic pain problems after standard pain-clinic interventions was most strongly associated with a belief that they had been given a full and complete assessment, and provided an explanation for the treatments that were being delivered; satisfaction correlated only weakly with pain relief.²⁸ In orofacial pain, the quality of the caregiver's communication can account for up to 15% of the variance in patients' satisfaction with the treatment outcome.²⁹

While it is reasonable to expect the findings above from varied persistent-pain populations also to be true in orofacial pain, only a direct study can ascertain whether this is the case and to what extent patients' beliefs and fears about the causes/maintenance of their orofacial pain change following their first consultation at a specialist facial pain clinic. The aim of this study was to explore patients' understanding of their orofacial pain, as this is an under-researched area despite emerging as a common aim of consultation. It was predicted that after the consultation, patients would understand their pain within a chronic pain framework, with accompanying reduction in anxiety.

Materials and Methods

Design

A qualitative approach, with semi-structured interviews before and after the initial consultation as well as written narratives afterwards, was used to explore how fears and beliefs about pain developed follow-

ing a consultation at a specialist pain clinic. The initial consultation took place with either the lead consultant or one of two specialist registrars trained by the consultant. Further details of the initial consultation are provided in the article by Napenas et al.³⁰ Ethical approval for the study was obtained from the Central London Research Ethics Committee.

Selection of Participants

The study was carried out in an orofacial pain clinic. Referral letters of patients waiting for an initial consultation were read to identify those at least 18 years of age with chronic orofacial pain of nondental origin. Individuals were excluded if they had previously been seen at the clinic, had a current diagnosis of cancer or a degenerative cognitive disorder such as dementia, or required an interpreter. Those meeting the criteria were invited to take part in the study (approximately 150 letters were sent out); individuals who opted in were telephoned by the researcher to check the criteria and arrange an interview. Informed consent to participate was obtained at the initial interview. Recruitment was stopped after 12 participants because the saturation of themes (see explanation of thematic analysis in section on Data Analysis) had been achieved.³¹

Procedures

There were three stages of dialogue between the researcher and participants and two self-report measures.

Part 1: Preconsultation Interview. A face-to-face meeting between the researcher (CB) and participant was conducted one or two days before the patient's first consultation at the pain clinic. A semi-structured interview schedule was devised for this study following the review of relevant literature. Minor changes to the structure and question content were made after piloting. The interview explored the patient's fears and beliefs about the causes and maintenance of his or her pain, the journey to the point of referral to the pain clinic, and hopes for the consultation. It was audiorecorded and lasted 35 to 50 minutes.

Part 2: Letter to the Researcher. At the end of the preconsultation interview, participants were asked to write a letter the next day to the researcher. A guidance sheet invited them to write approximately one side of an A4 page and indicate what they learned, what they did and did not find useful, and whether anything had changed following the consultation.

Part 3: Postconsultation Interview. The researcher contacted the participants to arrange the postconsultation interview, which would be conducted by telephone to eliminate travel. This semi-structured interview took up to 15 minutes and was audiorecorded. It was designed to identify

any changes in fears or beliefs about pain; it also inquired whether any diagnosis was given and the participant's thoughts on this. Where relevant, it followed up points raised in the postconsultation letter. Audiorecordings of pre- and postconsultation interviews were transcribed by the first author during the same time period as the data collection.

Self-Report Data. Two self-report measures, the Brief Pain Inventory (BPI) and the Hospital Anxiety and Depression Scale (HADS), were completed preconsultation and 1 week postconsultation. Preconsultation completion is routine in the clinic and was not associated with the researcher carrying out interviews. Postconsultation measures were specific to the study and mainly for descriptive purposes.

The BPI³² is a 15-item, self-administered questionnaire assessing the severity and impact of pain. Originally designed for cancer patients, it performs well in chronic noncancer populations,³³ including facial pain.^{34,35} The average pain and worst pain reported by the participant were used as descriptive data; interference was based on the mean of the 7 items, scored 0 (no interference) to 10 (completely interferes).

The Hospital Anxiety and Depression Scale (HADS)³⁶ is a 14-item self-report measure of distress in nonpsychiatric medical patients. In a review of 747 studies assessing the reliability and validity of the HADS,³⁷ mean alpha for internal reliability of the anxiety subscale was .83, and of the depression subscale .82. More recently it has been argued that the anxiety and depression subscales should be combined to create a single measure of emotional distress,³⁸ as done in the present study. Total scores can therefore range from 0 (no distress) to 42 (maximum distress).

Data Analysis

First the audiorecordings were transcribed verbatim by the researcher (CB), who reflected on each transcript, making brief notes on key points. These transcriptions and the postconsultation letters from the participants were analyzed using thematic analysis (TA). The aim of TA is to identify the meaning given by participants to the topic under investigation and to identify themes that are valid across participants.³⁹ TA was chosen because it enables the development of a set of themes that capture patterns in textual data, and it allows for interpretation of the themes in relation to the research question.

Information provided by the participants in the preconsultation interview about their pain experience and current management was treated as contextual. The remaining data were assigned codes (labels that were attached to sentences or phrases, dividing the data into units so that patterns could be identified). These were then grouped into categories and

compared across each transcript to identify similarities and differences and to ensure that the list was comprehensive. Frequently occurring codes were highlighted; note was also taken of codes that were unique to a particular participant.

Next, the coding categories were combined where content was similar, creating superordinate and subthemes, and split where heterogeneous. Groups of categories that appeared to form sequences were entered into flow diagrams to represent processes of development in understanding. Several examples of coded transcripts, the coding table, and the themes were checked by a coauthor (AW) experienced in qualitative analysis and chronic pain for validity of themes. Differences of interpretation were discussed, and themes were refined by consensus.^{31,39} The themes were then compared across the three occasions and collapsed where no differences were evident.

Results

Twelve patients (three men and nine women), aged 26 to 73 years, took part in the study. Table 1 provides the details of the patients' pain experience.

Thematic Analysis

Analysis of the data resulted in 12 subthemes that were clustered into four superordinate themes. The three data sets per participant were analyzed separately, as preconsultation interview, postconsultation letter, and postconsultation interview. However, no theme was specific to any of the three occasions, and all were evident, in varying intensities, on each occasion. Furthermore, it was not possible to identify differences over the period of 1 week between the written letter and follow-up interview. Data (as themes) were therefore combined, with annotation of whether and how they changed from before to after the consultation. Processes of developing understanding over time are described below, with subthemes from both the pre- and postconsultation data.

Theme 1: Need for Information to Counteract Helplessness

This theme concerns the impact that lack of information had on participants' sense of helplessness and hopelessness.

Uniqueness of Orofacial Pain. For some participants, orofacial pain had specific features that made it especially difficult to cope with.

"I can't even get to it . . . to soothe it. I keep thinking if it was in my leg, I'd just have my leg amputated. That's it: I'd just get rid of it, but you can't get rid of your head." (participant 10, preconsultation)

Table 1 Summary of Pain Experience

Participant no. (sex)	Age category (y)	Onset of pain + trauma, illness, or dental problems at onset (duration of pain)	Description of pain (Diagnosis given following consultation)
1 (Male)	40–59	Gradual (3.5 y)	Variable, nose and eyes, headaches (Chronic migraine)
2 (Male)	40–59	Sudden + trauma (17 y)	Constant, cheek, occasional "electric shock," toothache (Trigeminal neuropathic pain)
3 (Female)	40–59	Gradual + trauma (41 y)	Variable, eyes and ears, headaches, toothache (TMD and chronic idiopathic facial pain)
4 (Female)	40–59	Sudden + dental problems (1 y)	Variable, teeth, some "electric shock" (Atypical odontalgia and TMD)
5 (Female)	40–59	Gradual + trauma (30 y)	Eyes and cheeks, toothache (Chronic idiopathic facial pain and TMD)
6 (Male)	20–39	Sudden + illness (6 mo)	Constant pain in mandible, sensitive teeth (Chronic idiopathic facial pain and neuropathic pain)
7 (Female)	60+	Gradual (10 y)	Tender cheeks and eyebrows (Chronic idiopathic facial pain, mild TMD and sinusitis)
8 (Female)	20–39	Sudden + dental problems (2 y)	All teeth excruciating (Atypical odontalgia and TMD)
9 (Male)	40–59	Sudden (8 mo)	Face and jaw (Dental pain and possible trigeminal neuralgia)
10 (Female)	20–39	Sudden + dental problems (1 y)	Constant jaw pain (Trigeminal neuropathic pain)
11 (Female)	40–59	Gradual + dental problems (20 y)	Constant temporomandibular joint pain, toothache (TMD and worn dentition)
12 (Female)	20–39	Sudden + illness (2.5 y)	Side of head (Neuralgia)

BPI = Brief Pain Inventory; HADS = Hospital Anxiety and Depression Scale.

Difficulties Associated with Lack of Information Requiring Professional Input. Descriptions of helplessness frequently coincided with comments about lacking information about the condition, such as having no explanation for pain or guidance about managing it, and associated difficulties such as worry about exacerbating pain.

"I found . . . a video of exercises you could do, pushing your jaw in and out, and I did try that for a week. My jaw's initial reaction was a lot of pain, but then it did seem to get a little bit better. I thought: I don't know if this is right or not for me; I'm not sure if I should be doing this . . . am I making it worse?" (participant 6, preconsultation)

Some participants reported attending more to pain because they lacked understanding.

"It's just that I've become very sensitive to finding a solution. So I'm feeling things that I generally wouldn't have felt because I wouldn't have been conscious of them." (participant 1, preconsultation)

All participants described a strong desire to understand their condition better, and most had gone to considerable lengths in searching for information. Almost all valued personal encounters with professionals over other sources of information.

"Even though I haven't come away with a cure, I feel in a better position to cope with my symptoms." (participant 4, postconsultation)

Helplessness and Hopelessness. A set of codes that appeared frequently across the majority of preconsultation transcripts concerned the helplessness and hopelessness of chronic pain.

"I don't want to think 'this is it,' sort of waiting to die to be out of pain." (participant 10, preconsultation)

"So it sort of feels as if I have to just wait, either till it gets worse or it disappears on its own." (participant 1, preconsultation)

Information as Confusing or Inconsistent. It was clear that sometimes patients had rejected information provided by professionals because it conflicted with their existing understanding or with information from other professionals. For others, erosion of their trust in doctors or a feeling of being dismissed had impacted on their willingness to accept information. This appeared to change postconsultation, with information considered more trustworthy. Even those who reported unwelcome information about their prognosis were able to use it to change the way they managed their pain.

" . . . you don't necessarily always want to tell them that they are in the wrong because they are the ones who are the doctors." (participant 3, preconsultation)

"I knew about this before as well, but to be honest I was reluctant to follow advice from psychologists—relaxation and so on. I knew about this before but I did nothing." (participant 11, postconsultation)

Previous treatments other than medication	Preconsultation pain scores: average, worst	BPI interference pre, change post	HADS distress pre, change post
Physical	6, 8	8.2, -1.7	23, -2
Alternative, multiple surgeries	8, 10	6.5, -1.8	25, 0
Alternative, removal of teeth	7, 10	9.4, -1.2	40, 0
Psychotherapy	2, 5	2.4, -0.7	9, 0
Removal of teeth	3, 4	1, -0.3	22, -9
Physical	4, 6	3.4, -3	11, -6
Alternative, dental	5, 7	2.8, -2	13, -1
Dental	5, 8	3, +3.4	19, -5
None	2, 2	1.6, +0.5	10, +2
Removal of teeth, dental	7, 9	6.2, 0	13, -2
Dental	5, 5	2.1, -1.4	29, -8
Physical	4, 6	4.1, -0.6	15, -10

The transcripts suggested that patients did not always receive information as doctors intended it, so it was not simply a lack of information that led to hopelessness, but a lack of information compatible with existing understanding and/or an absence of explanation and personalization of the information.

Theme 2: Worry as Part of the Process of Making Sense of the Pain

This theme relates to fears and beliefs about the causes of pain—an area of mystery to most patients—and confusion where patients' firmly held theories had been disproved by scans or tests. There was also surprise that the face could be so painful. *"And surely these days with everything that can be done in the world, I mean they can transplant your whole face. Surely they can find [a cure]."* (participant 10, preconsultation)

Perhaps in an attempt to make sense of this, most participants appeared to be seeking answers to key questions about the pain, with implications for how they managed it.

Fear that Pain Signals Something Even Worse than Pain Itself. Several participants were burdened by worry that their pain might signal something more frightening, such as multiple sclerosis.

"Also because pain can be linked with other conditions like MS [multiple sclerosis], so suppose it's an

early indicator of MS? I don't know whether that's a brain thing that the MRI can say if it's not MS." (participant 9, preconsultation)

Worries of this nature were markedly reduced after the consultation, which frequently had a positive impact on people's relationship with their pain.

"I guess I'm just a bit calmer about the whole business . . . I think it just makes you more aware, because it's now quite a small pain; but if you concentrate on it, you start to amplify the sensation." (participant 9, postconsultation)

Fear that the Pain Persists Because Something Curable Has Been Missed. For other participants, or at other times, the worry was that something treatable had been missed.

"Part of me thinks it's that simple that everyone's overlooking it." (participant 10, preconsultation)

After the consultation, this was more persistent than worry about something more serious.

"I think I'd rather she showed me a scan and said 'this is all clear' . . . just to go on her gut feeling, or a questionnaire and symptoms, it felt a bit dismissed too fast really." (participant 10, postconsultation)

Two participants expressed neither of these fears before the consultation. One already had a satisfactory explanation for her pain (participant 12); the second (participant 3) was fully committed to her original theory and seemed unconvinced afterwards.

Dealing with Worry. Participants varied in how preoccupied they were by their worries. Some ruminated about their pain before the consultation and described no longer ruminating afterwards when they accepted that there was no undetected serious disorder; others were not preoccupied by worry before consultation but nevertheless described less anxiety afterwards.

"When I first had it I got quite obsessive about it, always dwelling on it. Whereas now I can compartmentalize it in my brain, think 'oh my jaw is hurting' and put that to one side and get on with other things instead." (participant 6, postconsultation)

Theme 3: Validation of the Pain Experience

This theme describes the importance that participants placed on having their pain experience validated by the pain clinic staff.

Misunderstood and Dismissed. Many patients were concerned that because their pain was invisible and had no diagnosis, they might be thought to be inventing it; some even feared that they might be amplifying it by some perverse psychological mechanism. It may be that it is particularly difficult for patients to explain orofacial pain to others. Other than dental and sinus pain, there did not seem to be a shared concept of facial pain to which patients could refer when explaining their experience to others.

"How do I know I'm not making it up? I don't know, maybe I'm making it up. There is no visible evidence of what is going on here." (participant 6, preconsultation)

"You have something that to you is very painful, but actually doesn't seem it to other people. I mean there is no reason why other people would think there is anything wrong with me. I can walk, I can go and get myself a drink, I am totally normal, and yet only I know the pain." (participant 8, preconsultation)

Postconsultation, diagnoses and explanations helped participants to feel that their experience of pain had been validated.

"[the doctor] went through a lot of trouble to explain how nerves in my body have basically got rewired the wrong way . . . it makes a lot of sense and I definitely trust her diagnosis (chronic facial pain) . . . just to have a name means that I can go away, look up as much as I can about the pain and how people live with it." (participant 8, postconsultation)

Diagnosis and the Desire to Make Pain Visible.

A common theme was a desire for some sort of visual proof of their pain experience.

"I'd like to get a Stanley knife and cut the side of my face open so I could see what is in there. That's the only way you're going to see." (participant 2, preconsultation)

"A couple of weeks ago, a woman that I manage said that my jaw looked swollen, and it was the first

time someone said it looked different. And I nearly kissed her; I thought, 'you can see it?!'" (participant 6, preconsultation)

This desire for pain to be made visible appeared to have several functions for participants: validation and confirmation of the reality of their pain, otherwise a very private experience, and entitlement to seek support, including support from others with the same identified problem.

"Maybe then [if I had a diagnosis] there are things I can do, like support groups. I don't even know if I would want to go to one, but knowing that they are there, that there is an option, some sort of community spirit thing." (participant 4, preconsultation)

Several participants also alluded to a belief that a positive test and/or a diagnosis would automatically lead to a cure.

"But on the other hand, if it was there [on the scan], at least I'd know there's something that can be done about it." (participant 9, preconsultation)

Another common expectation was that diagnosis would require scans and tests, so several participants were surprised that much of the diagnostic process was based on history taking. However, almost all were able to accept the diagnosis and explanation given to them, and diagnosis itself appeared to alleviate worry.

"I was quite relieved to have a diagnosis . . . although I had hoped I would come away with a solution for a cure, I am happy now that I know the cause and that it is not serious." (participant 2, postconsultation)

For some, this enabled them to abandon an exhausting search for answers.

"I guess what the appointment has done is drawn a line under it and made me think, well, that's fine, but nothing can be done about it so I just need to get on with things." (participant 5, postconsultation)

Overall, it seemed that all participants had been seeking some sort of certainty, in diagnosis, prognosis, and, for some, the legitimation of their pain. Their acceptance of this appears to be linked to the processes described in the following theme of trust.

Theme 4: The Importance of Trust

The final theme relates to participants' expectations for the consultation and reflections afterwards on the significance of the consultation.

Expert Status Attributed to the Clinic. The first interview elicited expectations about undergoing tests, ie, receiving a diagnosis and learning about treatment, and a sense of optimism about the possibility of finally obtaining the information that had long been sought, whether diagnosis, explanation, or specific guidance on pain management. Sometimes this was combined with investment in being seen by the lead consultant:

"It's about the only time I've ever felt, this could be the one. Purely because I've heard so many good things about [Professor]." (participant 10, preconsultation)

Giving up the Invasive Treatments, Search for Answers, and Worry. After the consultation, the majority of patients reported that a change had occurred as a direct result of the consultation. For some, this was a new understanding of their pain; for others, it was abandoning the pursuit of invasive treatments or of answers in general. A number of patients described having had their minds put at rest or feeling more able to cope. Importantly, this theme only emerged postconsultation.

"Even though I haven't come away with a cure, I feel in a better position to cope with my symptoms." (participant 4, postconsultation)

Acceptance of Diagnosis and Prognosis Without the Hoped-for Investigations. The changes that occurred demonstrate that patients largely trusted and accepted the information given to them during the consultation, even without the imaging investigations that many anticipated. They described feeling listened to and understood, and having had the diagnosis clearly explained in the context of the expertise of clinic staff.

"I felt the professor listened to me more than the other health care professionals I have seen and took into account the effects the pain was having on my life in general, rather than just treating me as a diagnosis." (participant 4, postconsultation)

"[The professor] spoke to us in ways that we understood, explaining everything in layman's terms. I was expecting a cure for the pain but did understand the reasons why there is not one." (participant 2, postconsultation letter)

There were exceptions to this: Three of the 12 participants were left disappointed by the consultation, which had not led to any changes for them. Examination of the transcripts revealed that two had held very specific hopes and expectations for the consultation, which were outside the remit of clinic provision: to have mercury fillings removed (participant 3) and to explore alternative therapies (participant 12); the third was referred elsewhere, leaving her frustrated with her pain clinic experience (participant 8).

Self-Report Data

In Table 1, the BPI pain data are given as raw scores preconsultation, as it was not expected that the pain would change immediately after consultation. However, the BPI interference and HADS data are shown as raw scores before and change after the consultation. Eight of the participants had lower distress scores postconsultation (median change -4.5). Although an immediate change in pain interference was expected, two participants showed a meaning-

ful decrease in pain interference postconsultation (a change in BPI score of 2 or more may be viewed as clinically meaningful).²⁴

Discussion

Summary of Results

The identified themes attempted to capture changes as a result of the specialist consultation; therefore, they contained subthemes from both the pre- and postconsultation interviews and letters. The themes captured the concerns of the pain patient arriving for a first specialist consultation: a desire for information and understanding to counter helplessness; specific worries about the meaning of pain; hopes rooted in the expertise of the clinic; and desire for validation of the pain experience.

Before consultation, most participants described gaps in their understanding, which exacerbated fears of inadvertently making their pain worse or missing opportunities to improve it, and a sense of helplessness and hopelessness. However, diagnosis and explanation alone, as became evident from postconsultation accounts, were not sufficient for all participants to feel they fully understood their pain, as some new information was difficult or impossible to incorporate in their existing understanding. The process of worrying about pain, attempting to find a solution, seeking validation of experience (to allay fears about unreality of pain), and searching for resolution of the pain had occupied several years for most patients before they reached the specialist clinic. An important fear was expressed as two variants: that something curable had been missed, perhaps anticipating eventual relief from pain, or that the pain signaled something more serious than had yet been discovered, a more pessimistic outlook.

The most evident changes occurred in relation to the worry that the pain signaled something more serious; the expertise of the clinic staff and the explanations given resulted in marked reductions of anxiety and distress. The worry that something curable had been missed was less well addressed by the consultation, and a minority of these patients recorded unchanged anxiety postconsultation.

Also before consultation, many of the participants were seeking scans and tests to validate their pain. This may be in part iatrogenically generated; the result of feeling or being disbelieved and dismissed by previous health care staff, importantly by primary care physicians or dentists, to whom facial pain may be unfamiliar, inexplicable, or understood in the context of psychosomatic disorders.^{16,40} Several patients expressed erroneous beliefs that diagnosis would imply availability of a cure. Postconsultation, despite not

having had scans or tests, and the realization that diagnostic labels did not lead to cures, explanations of the pain served important functions for participants, including the alleviation of worry and the decision to abandon the pursuit of further explanations.

Postconsultation, almost all participants described better understanding of the cause of the pain and/or changed intentions for pain management, and most showed a significant reduction in distress and/or pain interference; the theme of helplessness was virtually absent postconsultation. Importantly, it emerged that the expertise attributed to the orofacial pain clinic enabled most participants to accept diagnoses and prognoses and to adopt new understandings, even without the hoped-for scans and tests, and for some patients this meant moving from the search for an answer to plans to engage in new treatment and rehabilitation attempts. Furthermore, several patients showed reduced anxiety, which may facilitate reengagement with activity.

Worry

Themes emerging from this study are highly consistent with the characterization of worry as an attempt to solve a problem⁵; the process of worrying serves to help patients seek to understand their pain and, where they suspect the cause is not yet detected, it underlies efforts toward discovering it. However, for individuals with chronic pain, worry can become “misdirected,” trapping them in a process of repeatedly attempting to solve the insoluble problem of chronic pain^{4,5} and worrying that continuing pain has serious consequences predicting pain-related disability.⁴¹

Pain-related fears are easy to acquire but difficult to extinguish,⁴² and worrying about chronic pain maintains vigilance for pain and other somatic sensations,⁴ including those of no importance. Reassurance in medical settings is intended to minimize patients' worries, but it is often transient⁴³ and may even increase reassurance-seeking behavior.⁴⁴ An explanation that the patient can understand, recall, and use to counter worries can help that patient towards self-management. However, primary-care doctors underuse explanation for such patients.⁴⁵

While a lack of information can exacerbate helplessness, educating patients on their chronic pain condition can probably only achieve its aims when patients feel understood and trust the person who imparts that information, usually a doctor. For information to have a significant impact on freeing a patient from the “worry trap,” it needs to have sufficient authority and to be delivered in the context of the patient feeling heard and believed. Receiving a clear explanation about their pain and its prognosis helped some participants to make positive changes to their lives: to stop worrying and to give up their exhausting

pursuit for a cure. Their descriptions of planning to “get on with life” after receiving often difficult news about the prognosis of their conditions recalled descriptions of pain acceptance.⁴⁶

Validation

Almost all patients expected scans and tests, even though structural abnormalities may be absent or irrelevant.⁴⁷ The wish for visible evidence may be more about legitimization of the chronic pain experience²² than about diagnosis. However, participants who had hoped for scans but received instead a consultation based on history taking (lasting 45 to 60 minutes) were largely satisfied with the diagnosis and explanation that they received. This appeared to be due to a combination of feeling that the doctor understood them, having the diagnosis clearly explained, and the expert status attributed to the clinic. This is in contrast to the findings of Wolf and colleagues,¹⁷ whose orofacial pain patients were dissatisfied with consultation largely on the basis of not feeling believed or cared about.

The three patients who were disappointed by the consultation appeared to have been referred inappropriately: two sought specific treatments not provided by the clinic rather than resolution of concerns about the nature of their pain and diagnoses. Clearer information on what treatments were offered by the clinic would have avoided wasted consultations for these two, and the clinic has been informed of this. The third patient was referred for dental investigation and treatment that should have been done prior to referral to the orofacial pain clinic.

Strengths and Weaknesses

This study provided an in-depth understanding of the fears and beliefs about orofacial pain that many patients bring to a consultation and how changes in these cognitions, as a direct consequence of the consultation, can lead to positive changes in the experience and management of pain. It therefore underlines the importance of the expert consultation process as a significant intervention in its own right, a problem given the enormous disparity between need and resources.¹⁹ It also underlines the extent to which many aspects of the experience of chronic orofacial pain¹³ are shared with other chronic pain patients described in the literature,^{48,49} albeit that some orofacial pain patients in this study asserted its uniqueness.

The main shortcoming of this study was that since they consulted different doctors, patients may have received different styles of consultation and pain explanations. The authors considered this against the problems of studying patients of only one consultant, with risks to generalization, and knew that the clinic made active efforts to use and disseminate a consistent model of chronic pain.¹³ Further, except in one instance,

clinicians were unaware of which patients had agreed to the study, so while there might be between-doctor differences, the authors believe the data reflected each doctor's usual consulting behavior. Patients' behavior in the consultation, however, may have changed as a result of the preconsultation interview and of anticipated further contact with the researcher, despite the fact that she was not affiliated with the clinic.

A repeat of the study would have the telephone interview on the day after the consultation, providing a space for the expression of any frustration and the opportunity to prompt reflection, before giving participants a week to complete the written narrative, rather than the opposite order as in this study. Despite the small sample, saturation appeared to be reached in extracted themes, although a larger sample size might enable a richer or more detailed account, and in particular, further exploration of changes postconsultation. Additionally, the quantitative data collection was intended for description of change; a replication would power the contrast to allow more rigorous analysis than was possible in this study.

Clinical and Research Implications

This study showed that a single consultation (adequate in terms of content and length) can have an important therapeutic effect. A first consultation is often represented solely as assessment, when it can be a crucial exchange of ideas and understandings, reaching a consensus on the best way forward. Classifying it as assessment seriously underrepresents the potential for pivotal change, which it could be argued should lead to fewer expensive investigations, reduced ineffective health care utilization, and fewer costs to the health care system in the longer term. Testing those hypotheses is feasible in longitudinal studies. Finding ways to provide the valued content and process of these consultations at an earlier stage of patients' pain journeys should also reduce human and economic costs of chronic pain. Further studies could be designed to investigate the relationship between changes in beliefs and understanding of pain as well as changes in health care use and self-management over the longer term. In particular, themes identified here could be used to sample populations on specific concerns.

A further hypothesis generated by this study is that there are two distinct forms of worry about pain in relation to diagnosis: (1) that something more serious than pain has been missed and (2) that a curable cause has been missed. These two forms of worry also merit further investigation, since they require different processes to resolve them. It is not clear to what extent well-written, authoritative, and relevant information could substitute for the functions that were valued by pain patients in this study. It is difficult for generic information to enable patients to feel "listened to" or un-

derstood, which for many is a precondition of changing their understanding of pain and the resultant worries. This study has demonstrated that patients have differing needs from consultations, and further research might explore how explanations can be tailored to take into account existing fears and beliefs.

Conclusions

This study has shown that patients' fears and beliefs about chronic orofacial pain are associated with processes of worrying and searching for meaning. Information about their chronic pain condition is most likely to counter patients' helplessness and enable them to make sense of and manage their pain when explanations are clear, delivered by a trusted health care professional, and take into account their existing health beliefs. Importantly, most patients who hoped for tests to validate their pain were able to accept diagnoses and explanations without them. These findings underline the important functions of specialist consultation in achieving a shared accurate understanding of pain and of appropriate treatments. However, it requires time and expertise, which are in relatively short supply and therefore unavailable to many patients struggling with chronic pain. Political and financial pressures to restrict access to secondary care will make it unavailable to many more until ways are found to fulfill these functions adequately in primary care.

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