JQRHS

Journal of
Qualitative Research in Health Sciences

https://jqr1.kmu.ac.ir
10.34172/jqr.1426
JQRHS. 2025;14:1426

Original Article

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# Patient Perspectives on Living with Chronic Orofacial Pain: A Qualitative Study

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**Abstract**

**Background:** Chronic orofacial pain (OFP) is a serious public health issue that significantly affects the quality of life of patients, contributing to anxiety, anger, and depression. While many studies have focused on the quantitative assessment of pain, very few have addressed the quality of life in these patients. Qualitative research offers a naturalistic, interpretive approach to explaining or understanding human experience. Accordingly, this study aimed to explore patients' experiences with chronic OFP.

**Methods:** This qualitative study involved 16 patients with chronic OFP. A phenomenological approach was adopted to foreground the subjective experiences of individuals. In-depth interviews, lasting 60-120 minutes, were conducted using open-ended questions about experiences of symptoms, treatments, and living with OFP. Interviews were digitally recorded and transcribed verbatim. Thematic analysis was employed to identify themes across biomedical, psychological, and social dimensions. Following coding, representative quotes were presented to illustrate the themes.

**Results:** Analysis revealed several themes and subthemes demonstrating the significant impact of chronic OFP on quality of life. Deprivation of social contacts led to feelings of helplessness and disbelief among family members and to loss of employment. Adverse cognitive effects impaired coping with pain and were associated with physical agony, taste alteration, and inability to perform routine activities. Disbelief in the healthcare system was a major agony, influenced by prolonged medication use, multiple referrals, and perceived lack of empathy from physicians.

**Conclusion:** This qualitative study provided an in-depth analysis of patients' experiences of living with chronic OFP. Cognitive, social, and cultural factors can alter pain coping mechanisms, pain perception, and trust in the healthcare system. The findings from this study highlighted gaps in current care and suggested that comprehensive management, potentially including cognitive-behavioral therapy, lifestyle modifications, and alternative treatment modalities, along with occupational therapy and timely referral to pain specialists, may support holistic healing and improve functioning.

**Keywords:** Chronic pain, Depression, Anxiety, Patient experience, Qualitative study

**Citation:** Patil DJ, More CB, Venkatesh R. Patient perspectives on living with chronic orofacial pain: a qualitative study. *J Qual Res Health Sci*. 2025;14:1426. doi:10.34172/jqr.1426

**Received**: April 30, 2024, **Accepted**: March 20, 2025, **ePublished**: August 16, 2025

## Introduction

Orofacial pain (OFP) is a subjective and complicated phenomenon that causes substantial discomfort and suffering and is the most prevalent symptom of dental and oral disorders. It is a serious public health issue that can significantly affect quality of life and is one of the main reasons people seek oral healthcare services (1-3). OFP is defined as pain perceived in the face or mouth region. Chronic OFP is a term used to describe painful regional syndromes that follow a chronic, unremitting pattern and may be subdivided into three main symptomatic classes: musculoskeletal, neurovascular, and neuropathic (4). The National Center for Health Statistics (NCHS) generally uses a cutoff point of three months to distinguish acute from chronic pain. The estimated prevalence of chronic pain in the general adult population worldwide varies from 14% to 42%, of which 7-11% is chronic OFP (3).

Due to the complex regional anatomy of the orofacial region and the difficulties in diagnosing and treating chronic pain conditions, many regional pains present as recurrent, persistent, or disabling patterns. Persistent OFP frequently results in consultations with primary dental or medical centers and onward referrals to specialist services. Patients have their own perspectives on their pain conditions. Psychosocial factors are important risk factors for developing chronic OFP. Affected individuals may experience social isolation, daily challenges in routine activities, and dissatisfaction with the healthcare system (5,6). Chronic pain adversely affects both physical and psychosocial well-being. Living with chronic pain can be an extremely negative experience, influencing all aspects of a person's life. Chronic pain causes significant distress,

leading to anxiety, anger, depression, sleep disorders, loneliness, and altered self-image and identity, along with a significantly reduced quality of life (7). Numerical rating scales (0 to 10), visual analog scales, or diagrams have been predominantly used by healthcare professionals to measure the intensity of pain. However, pain assessment remains controversial as defining pain is inherently subjective and may vary significantly from one person to another (8).

The prognosis for chronic OFP is variable, and only a minority of patients recover to their previous level of health. Patients with atypical pain consult 7-20 doctors on average, with investigations often failing to reveal an organic cause. Finally, these patients are categorized as medically unexplained (9,10). Qualitative research investigates human experience through a naturalistic and interpretive lens to make sense of or understand the phenomena in question. Such approaches can offer insights into the pain experiences that have not been adequately understood or explained by the scales and tools used in most existing quantitative studies on chronic pain (11).

To study chronic pain effectively, an interpretive phenomenological approach is employed since it provides deep, nuanced understandings of participants' sentiments. This approach is appropriate when the researcher intends to explore the meaning of the phenomenon by focusing on participants' lived experiences and how they make sense of them (12,13). Previous studies have largely emphasized quantitative assessments of pain through scales and questionnaires, with limited exploration of the biomedical concepts of pain. The review of literature revealed a paucity of research on the experience of living with chronic OFP (13,14). The research hypothesis posited that patients with chronic OFP experience considerable physical and psychological distress and lack effective pain coping mechanisms that impact their quality of life, with multiple treatments proving to be ineffective. Accordingly, the present study aimed to explore the experiences of patients living with chronic OFP who present for pain consultation through in-depth qualitative interviews.

## Methods

This qualitative study was conducted after obtaining ethical approval and informed consent from patients. Participants of both genders, aged 18 years or older, and experiencing OFP for at least three months were included in the study. Patients were categorized according to their OFP symptoms into neuropathic, neurovascular, musculoskeletal, and dentoalveolar pain. Participants with chronic morbidity or on antipsychotic medications were excluded from the study.

The COREQ guidelines for reports on qualitative research were followed in the preparation of this manuscript.

### *Study design*

The study adopted a qualitative design. Ethical approval and informed consent were obtained, and data confidentiality was maintained. A phenomenological orientation was used to study the lived experiences of patients with chronic OFP. Phenomenological research seeks to understand how individuals perceive, interpret, and make sense of a particular event, situation, or concept.

### *Participant selection*

As this is a qualitative study, a minimum sample size of three was deemed appropriate, and given the wide range of demographic data available, a maximum of 15-20 participants was finally considered. Data were collected through face-to-face in-depth interviews, which continued until saturation was reached. Based on the inclusion criteria, 19 patients were initially selected. Three patients dropped out because they were unwilling to cooperate due to personal issues. While dropouts may affect the generalizability of the findings and the interpretation of the phenomenon under investigation, the final study sample consisted of 16 patients, comprising a diverse group of patients with OFP.

### *Setting*

Interviews were conducted by the researchers in a designated area in the orofacial pain unit of the department. Participants were made comfortable and interviewed in a calm environment with no distractions to facilitate easy communication and reduce hesitation.

### *Data collection*

Table 1 presents the characteristics of OFP among study participants. Patients were categorized as having chronic OFP according to the criteria of the International Association for the Study of Pain (IASP) (15). Open-ended interviews explored participants' experiences with symptoms, treatments, and living with OFP. Interview questions covered current pain levels, the most recent incidents of pain, the most specific instances of pain, onset of pain, life before pain, potential instances of pain, and perceived shortcomings in healthcare delivery. Interviews lasted 60 to 120 minutes and followed a progression from less invasive to more detailed in-depth questions.

Interviews were digitally recorded and transcribed verbatim, with identifying information removed. Field notes capturing important observations were recorded by the researcher during the interviews. Each interview was transcribed verbatim by the first author and checked for accuracy by other researchers. Thematic analysis was conducted using Atlas.ti software (16). After thematic analysis of data and coding, representative quotes were presented. Textural and structural descriptions of participants' experiences were written in the report. Script development and data coding were performed by two authors.

**Table 1.** Characteristics of the study participants

| Participant code | Age/ Gender | Occupation | Orofacial pain characteristics | | | | |
|---|---|---|---|---|---|---|---|
| | | | Location | Onset time | Duration | Severity VAS | Diagnosis |
| 1 | 51/M | Farmer | Right Mandible, right side of the face | 1 year | Seconds – a few minutes | Severe-8 | Trigeminal Neuralgia-V3 (Right side) |
| 2 | 50/M | Tailor | Left Mandible, right side of the face | 2 years | Seconds – a few minutes | Severe-9 | Trigeminal Neuralgia -V3 (Left side) |
| 3 | 42/M | Laborer | Tongue, throat, buccal & labial mucosa | 10 months | A few minutes | Severe-9 | Primary burning mouth syndrome |
| 4 | 62/M | Farmer | Right side of the face Zygoma, Temporal region | 14 months | A few minutes | Moderate -7 | Atypical facial pain |
| 5 | 70/F | Housewife | Burning sensation in the oral cavity, Hyperesthesia | 2 years | Seconds – a few minutes | Severe-8 | Glossopharyngeal neuralgia |
| 6 | 50/F | Teacher | Left side of the mandible Shoulder, neck | 8 months | A few seconds | Severe-10 | Atypical facial pain |
| 7 | 43/F | Housewife | Burning sensation in the tongue, body ache, tingling sensation in the lower limbs | 2 years | Continuous pain | Severe-9 | Primary burning mouth syndrome |
| 8 | 57/F | Housewife | Lower right side of the face, Dorsal surface of tongue | 1 year | Continuous pain | Moderate -6 | Chronic neuropathic pain with burning mouth syndrome |
| 9 | 56/F | Housewife | Left side of the face | 5-6 years | Seconds – a few minutes | Severe-10 | Trigeminal Neuralgia -V2, V3 (Left side) |
| 10 | 43/F | House wife | Left side of the face, Preauricular region | 3-4 years | A few minutes | Severe-9 | Internal disc derangement without reduction |
| 11 | 68/F | House wife | Left side of the face, Preauricular region | 2-3 years | A few minutes | Moderate -6 | Myofascial pain |
| 12 | 45/M | Businessman | Pain and burning sensation in the oral cavity, pain in the back | 2 years | Continuous pain | Moderate -6 | Chronic neuropathic pain |
| 13 | 38/F | Skilled laborer | Pain on the right side of the face | 1 year | Seconds – a few minutes | Severe-9 | Trigeminal Neuralgia -V2 (Left side) |
| 14 | 23/F | Student | Pain on the right side of the face Preauricular region Masseter | 1 and a half years | Seconds – a few minutes | Severe | Myofascial pain |
| 15 | 59/F | Housewife | Pain and burning sensation on the gingiva and buccal mucosa bilaterally | 2 years | A few minutes | Severe | Lichen planus |
| 16 | 47/M | Businessman | Pain and burning sensation on the tongue and lower lip | 3 years | A few minutes | Severe | Primary burning mouth syndrome |

### *Data Analysis*

The researchers reviewed the interview transcripts repeatedly to gain an overall understanding of the data and identified units of meaning. Meaning units that comprised text segments related to the same content and context were extracted by dividing the text at points where meaning changed. Redundant terms were removed, yielding condensed meaning units. Each condensed meaning unit was coded to indicate its primary meaning, and codes were organized into themes and subthemes. Quotations illustrating observed patterns and interpretations were selected, with their English translations provided. Translations were performed by a subject-matter expert at the institute, with back-translation by a second expert (RV) to ensure accuracy. Content analysis focused on themes that connected people and experiences. Finally, a concept map was created to provide a concise summary of how chronic OFP experiences affect daily life, illustrating the focus question (OFP experiences) and the interconnections among themes and subthemes.

## Results

### *Characteristics of study participants*

The characteristics of patients included in the study are depicted in Table 1. The sample consisted of 10 female and 6 male patients with chronic OFP, aged between 42 and 70 years.

### *Themes*

During transcription, several relevant issues emerged. The participants' experiences were overlapping and interrelated (Figure 1). Table 2 presents themes and subthemes from the transcripts. Several codes were developed after the first interview. Figure 1 illustrates the content analysis and the coding process.

#### *1. Life before and after episodes of pain*

Participants reported that chronic OFP negatively impacted their daily life, including routine activities, social and family life, and mood.

##### *Impact on routine day-to-day activities*

*"In the past, I maintained a regular lifestyle and adhered to a routine of performing five prayers every day. While engaging in a prayer posture, I experience a brief but intense pain originating from the face and extending to the head, which subsides after a few seconds. Currently, I find myself unable to continue this practice"* (51-year-

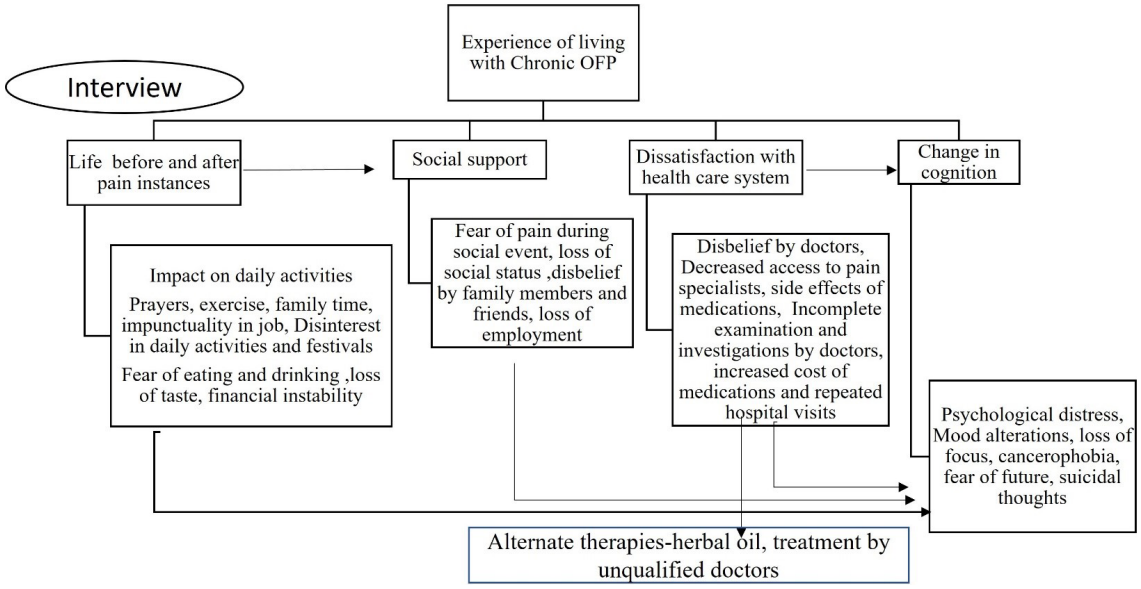


**Figure 1.** Content analysis of experiences of living with chronic OFP

**Table 2.** Themes and subthemes generated from interviews

| Themes | Sub themes |
|---|---|
| Life before and after episodes of pain | Impact on routine day-to-day activities<br>Inability to perform daily tasks<br>Loss of employment and financial instability |
| Impact on social life and support | Change in social status<br>Cessation of communication Feeling of isolation |
| Experience with the healthcare system | Lack of belief by physicians Dissatisfaction with investigations and multiple medications |
| Lack of healthcare infrastructure and pain specialists | Insufficient number of pain specialists—leading to misdiagnoses and multiple referrals |
| Effect on cognition | Mood alterations<br>Psychological impact and loss of focus<br>Cancerphobia |

old male patient with trigeminal neuralgia).

"*I would wait for the festival of lights. I no longer derive pleasure from celebrations. I am no longer able to enjoy the taste of my preferred meals. I believe that I am afflicted by a curse and will perpetually experience pain*" (70-year-old female patient with glossopharyngeal neuralgia).

"*I feel restless at night and upon awakening, experience fatigue in my facial muscles, with intense headaches in the temporal region, which significantly impairs my ability to focus on my academic studies and to carry out my regular morning activities*" (23-year-old female patient with myofascial pain).

"*I am experiencing acute numbness and pain in my mandibular region. Subsequently, the pain radiates to my back and legs, accompanied by a sensation of overall body weakness. I am unable to comprehend or understand any written material. I spend the entire day lying in bed. I currently lack a sense of purpose or direction in my life. I am eagerly anticipating the arrival of my demigod companion to accompany me. I desire to visit my ancestral deity as my final wish*" (45-year-old male patient with chronic neuropathic pain).

*Inability to perform daily tasks*

"*The intensity of the pain prevents me from waking up early in the morning, exercising, and meditating. I lock myself in my room and pretend to sleep all day*" (62-year-old male patient with atypical facial pain).

*Loss of employment and financial instability*

"*Currently, I am experiencing a state of lethargy and have ceased engaging in the activity of stitching. My children have discontinued their education and instead work daily at a nearby garage*" (50-year-old male patient with trigeminal neuralgia).

"*I experience sudden lockjaw, resulting in a partially open mouth. The intensity of the pain hinders my ability to engage in basic activities such as eating, sleeping, and focusing on my job. I am concerned about my future due to unemployment, reduced income, and financial difficulties*" (43-year-old female patient with internal disc derangement without reduction).

*2. Impact on social life and support*

Several participants reported a cessation of social life, with close acquaintances and relatives becoming unfamiliar.

However, a minority of participants reported receiving support from friends who encouraged them to maintain a positive outlook on life.

*Change in social status*

*"I refrain from attending social functions due to my fear of experiencing pain and of showcasing my singing talent. The inability to meet friends and relatives has led to feelings of depression and loneliness"* (43-year-old female patient with internal disc derangement without reduction).

*Cessation of communication*

*"I have ceased communication with my friends and relatives because speaking exacerbates my pain. I am unable to effectively convey my pain to my spouse, out of concerns for causing her distress regarding my condition and because of internal conflict"* (51-year-old male patient with trigeminal neuralgia).

*Feeling of isolation*

*"Due to my painful episodes, my family has stopped interacting with friends and relatives. The social life of my family has been hampered, with fewer family outings, and my children feel isolated"* (43-year-old female patient with internal disc derangement).

### *3. Experience with the healthcare system*

Participants' experiences with the healthcare system varied. Some expressed dissatisfaction with the doctors' lack of investigation into their issues and a perceived lack of empathy. The majority resided in remote locations with limited access to pain specialists.

*Lack of belief by Physicians*

"*After multiple consultations, physicians diagnosed my pain as of psychological origin. As there were no observable facial changes, my doctors dismissed it as excessive rumination*" (50-year-old female patient with atypical facial pain).

"*My physician didn't understand my pain due to the absence of apparent physical alterations. He advised me to accept and manage my condition without conducting a physical examination or diagnostic tests and dismissed it as an overstatement*" (67-year-old male patient with atypical facial pain).

*Lack of healthcare infrastructure and pain specialists*

"*Due to a lack of essential healthcare infrastructure, I was referred by the local physician to a tertiary health center for further evaluation. However, after multiple referrals, the doctors lacked competency and empathy, which intensified my pain*" (43-year-old female patient with internal disc derangement without reduction).

*Dissatisfaction with investigations and multiple medications*

"*The pain I experience has gradually worsened over several years. During each doctor's visit, I was dissatisfied with the diagnosis and consulted multiple physicians regarding my issue, underwent multiple investigations, and received prescriptions for various medications. However, it appears that everything is futile, and I have incurred significant expenses throughout this entire process. The doctors have been unable to find a solution for my problem*" (70-year-old female patient with glossopharyngeal neuralgia).

"*Despite seeking treatment from multiple dentists and undergoing various procedures, I have yet to find relief from my persistent pain. I have been examined by multiple physicians who have subsequently referred me to different hospitals. Is there any physician who possesses the necessary expertise to understand my medical condition and provide appropriate treatment*?"(50-year-old female patient with atypical facial pain)

### *4. Effect on cognition*

Participants often modified their cognitive processes and responses to challenges as a result of chronic pain. Some individuals experienced a loss of interest in life, and a few even reported thoughts of suicide.

*Mood alterations*

"*I have experienced a shift in my personality, resulting in a pessimistic outlook on life. I have reached a point of resignation in my life where I no longer have hope for improvement*" (76-year-old male patient with postherpetic neuralgia).

*Psychological impact and loss of focus*

"*I believe that my current suffering is the result of a sin I may have committed in a previous life. I seek to visit sacred shrines, consult priests, and give charity to find relief from my suffering*" (57-year-old female with lichen planus).

*Cancerphobia*

"*I experience persistent anxiety due to pain and fear of an oral tumor. I have experienced a decrease in appetite and subsequent weight loss. However, my current physician is not conducting a thorough examination, and I perceive that my death is approaching and that I will succumb to cancer*" (57-year-old female patient with chronic neuropathic pain and burning mouth syndrome).

## Discussion

This study extended the current understanding of chronic orofacial pain (OFP) by providing a comprehensive account of the experiences of individuals living with this condition. A qualitative methodology was deemed

appropriate for exploring the lived experiences of chronic OFP. The term phenomenology originates from the Greek phaenesthia, meaning 'to show itself'. Hence, phenomenology is the study of phenomena as they present themselves. Interpretive phenomenology builds on the work of Heidegger, who viewed phenomenological study as an interpretive process (11-13).

In this qualitative study, several subthemes related to social deprivation and resultant helplessness, disbelief by family members, and loss of employment were identified. Participants reported insufficient coping mechanisms with pain, leading to physical agony, taste alterations, and the inability to perform routine activities. A major source of agony was disbelief in the healthcare system, manifested through prolonged medication use, multiple referrals, and perceived lack of empathy from physicians.

An important aspect of patient suffering was the negative impact on daily life activities, including nutrition, sleep, and coping with stress and anxiety. Similar results have been reported by Hazaveh et al. (13) and Wolf (14) et al. Patients' routine activities were compromised, and daily tasks appeared new and intimidating. Therefore, health providers should assess and manage patients' sleep, nutrition, and other self-care needs to maximize health and functioning (17). Referrals to services such as occupational therapy for modifications of daily living tasks may be beneficial for patients (18).

The most common complaints were related to biomedical pain management, use of multiple medications, and side effects. These findings are consistent with previous studies (19, 20). Pain specialists should include a discussion of these typical side effects in routine care to help patients make informed decisions about regimen costs and benefits. The health providers can change the route of medication, provide dietary fiber supplementation, and promote the use of alternative therapies like acupuncture and relaxation exercises to alleviate the frequency of OFP (21).

The findings also indicated significant cognitive and psychological impacts, such as anxiety, emotional stress, unpredictable or unknown pain, mood alterations, loss of focus, challenges in medication management, mood swings, and pessimism, along with coping mechanisms. The severity of pain was associated with depression, anxiety, and overall mental distress, particularly among patients with burning mouth syndrome (BMS), neuropathic pain, neuralgias, and temporomandibular disorders (TMDs). The unpredictable nature of pain emerged as a source of concern that affected patients' ability or willingness to engage in social activities and employment (22).

Research has shown that patients with BMS may exhibit higher levels of despair, anxiety, hypochondria, and cancerphobia in their psychological profiles (23). Psychosocial stressors can worsen parafunctional behaviors, elevate corticosteroid levels, or even increase TMD risk through sympathetic nervous system activation (24). Pain catastrophizing is commonly observed in patients with trigeminal neuralgia (25). These findings support previous research suggesting that psychological variables may contribute to the development of persistent OFP. Cognitive-behavioral therapy, relaxation, and biofeedback have demonstrated effectiveness as psychological interventions and may be useful for patients with persistent OFP (26, 27). The findings of the present study suggest that accessible programs should be integrated more frequently into routine care to address the unique psychological experiences of patients with chronic OFP (28, 29).

Several subthemes were identified in the social theme, such as problems in social relationships, duties and responsibilities, interactions with providers, socioeconomic factors, and access to care. The results of the present study are in line with other studies (19, 29-31, 13, 14) that demonstrate individuals with all types of chronic pain frequently perceive a lack of understanding from friends, family, and society at large. A cycle of loneliness, helplessness, sadness, and shifts in identity roles was identified, driven by isolation and altered social duties and responsibilities. Patients with OFP may benefit from collaborative, systemic approaches to treatment involving spouses and family members to address these social problems. Clinicians may also guide patients toward forums, support groups, and advocacy organizations for chronic OFP (19, 30). Loss of employment emerged as a significant problem faced by patients, imposing financial burdens. These findings align with a qualitative study by Mohr et al. (31), which documented that pain can have profound social consequences, leading to withdrawal from social contact and isolation.

Disbelief or distrust toward the healthcare system was another prominent subtheme. Patients frequently reported long, painful searches for pain relief and numerous unsuccessful therapeutic attempts. This finding is consistent with previous studies showing limited success rates (less than 25%) for treating persistent OFP (19, 31, 32). Many patients perceived a lack of empathy from physicians during examination and treatment, as echoed in studies conducted in Hong Kong (31) and the United Kingdom (3). Qualitative research on the management of chronic facial pain has shown that general practitioners and dentists often view these patients as challenging and unrewarding, feeling unprepared to diagnose or treat them, which can negatively affect patient care (33, 34).

A significant finding of the present study concerns the cultural background of pain patients. The majority had not completed formal schooling and were skilled laborers from rural areas (Table 1). This could have impacted pain communication, coping strategies, and belief in the healthcare system. These findings provide an updated

perspective on the concurrent and interconnected problems associated with chronic OFP. The study also revealed that cognitive impairment can affect emotional and behavioral responses, thereby modifying pain perception and coping strategies. Patients may feel stigma, social isolation, and frustration, all of which can impact patient-physician interactions, treatment adherence, and effective healthcare utilization. A holistic approach to chronic OFP management should include psychological interventions, such as cognitive-behavioral therapy, to address cognitive and emotional factors that contribute to pain and disability.

The qualitative design enabled a deeper contextual understanding of the feelings and behaviors of patients with chronic OFP. The study location and setting – a pain clinic serving as both a primary-care provider and a referral center for nearby health centers and general practitioners – was advantageous. After 16 interviews, each lasting 60-120 minutes, data saturation was reached, suggesting the sample size was sufficient. Almost the entire spectrum of orofacial pain patients was investigated in this study. In qualitative research, emphasis is placed on context and meaning rather than creating a picture of the population that is representative, which is a recognized limitation. Besides, given the small sample size, it is not possible to generalize the findings to all patients.

## Conclusion

This qualitative study provided an in-depth analysis of patients' experiences of living with chronic orofacial pain (OFP). Cognition, social, and cultural factors can alter pain coping mechanisms, pain perception, and belief in the healthcare system. The findings illuminated gaps in the current scenario and supported the development of effective treatment protocols. A multidisciplinary team, comprising pain specialists, cognitive-behavioral therapists, and occupational therapists, should be engaged to provide effective patient-centered treatment. The findings of this study may inform professional associations, researchers, academic institutions, and funding agencies in formulating policies to advance OFP research and to guide clinicians in delivering tailored, holistic care.

### Acknowledgments

We would like to acknowledge the patients for participating in this study.

### Authors' Contribution

**Conceptualization:** Deepa Jatti Patil.
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**Supervision:** Chandramani B. More.
**Validation:** Rashmi Venkatesh.
**Visualization:** handramani B. More.
**Writing–original draft:** Deepa Jatti Patil.

### Competing Interests

The authors report no conflicts of interest.

### Ethical Approval

Ethical approval was obtained from Sumandeep Vidyapeeth Institutional Ethical Committee. (SVIEC/ON/DENT/RP/20048)

### Funding

This research project did not receive any funding.

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