




“I Still Suffer Every Second of Every Day”: A Qualitative Analysis of the Challenges of Living with Chronic Orofacial Pain

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Objective: Chronic orofacial pain is prevalent and debilitating. Psychological and social factors place a heavy burden on this population but are often overlooked. Here, we offer the first comprehensive qualitative conceptualization of the challenges of living with chronic orofacial pain through a biopsychosocial perspective to inform multifaceted care for this population.

Design: We employed a qualitative thematic analysis of open text responses using a hybrid inductive-deductive approach and a biopsychosocial framework.

Methods: Two hundred and sixty participants with chronic orofacial pain responded to an open-ended question: “What is the biggest challenge you face in managing your condition?” by typing their responses into a text box as part of an online survey. We mapped responses onto biomedical, psychological, and social themes (deductive) and concurrently identified findings within each theme that emerged directly from the data (inductive).

Results: Subthemes within the biomedical theme included challenges with biomedical pain management, medication side effects, sensory triggers, physical symptoms of stress/tension, and biological functions and related activities of daily living. Subthemes within the psychological theme included anxiety, depression, emotional symptoms of stress, unpredictability/uncertainty of pain, and psychological and cognitive aspects of medication management. Subthemes within the social theme included social relational, experience with providers, socioeconomics and access to care, and roles and responsibilities.

Conclusion: Chronic orofacial pain is associated with multifaceted challenges. Consideration of individuals’ experiences of biomedical, psychological, and social challenges in the assessment, referral, and treatment of chronic orofacial pain holds the potential to promote more comprehensive, patient-centered care for this population.

Keywords: chronic orofacial pain, biopsychosocial model, qualitative research, thematic analysis

Background

Chronic orofacial pain is one of the most common forms of chronic pain.^{1,2} It is defined by the International Classification of Orofacial Pain (ICOP) as pain in the face, mouth, or jaw that is present for at least 15 days in the past month and spans at least 3 months.^{3,4} Chronic orofacial pain often results in substantial disability^{1,5,6} and places a heavy burden on the healthcare system.^{7,8}

Chronic orofacial pain is largely conceptualized through a biomedical lens.^{9–11} Treatments for chronic orofacial pain similarly focus primarily on biomedical factors. Such treatments typically have low success rates,¹² adverse side-effects,¹³ and can include unnecessary and painful procedures (eg, tooth extractions, occlusal adjustment) that may result in permanent damage.^{9,12,14} Despite this biomedical dominance, a growing body of evidence illustrates the interplay between psychological and social factors and chronic orofacial pain symptoms and outcomes. These include psychological distress (eg, stress⁹ and hopelessness¹⁵ as both

risk factors¹⁶ and consequences of chronic orofacial pain^{1,17} as well as known social effects (eg, negative impact on relationships¹⁸ and decreased social quality of life¹⁹). To date, with temporomandibular pain as an exception, psychosocial considerations in orofacial pain management have received limited attention.²⁰ This highlights a need for a comprehensive approach to characterizing the multitude of challenges confronted by individuals with chronic orofacial pain to better understand the range of this population's needs.

The biopsychosocial model is a widely accepted approach for conceptualizing treatment for chronic pain.²¹ This model provides a useful framework for a more integrative assessment of these individuals' experiences, concerns, and priorities.^{20,22} Identifying specific biomedical, psychological, and social challenges is critical for informing comprehensive care for this population and working towards meeting the variety of its needs. Qualitative research methods can generate a nuanced understanding of these individuals' lived experiences and perceived challenges,²⁰ and using the biopsychosocial model as a framework in qualitative research is a promising means to inform implementation of psychosocial care.²³

The aim of the current study is to gain insight into the most challenging aspects of living with chronic orofacial pain based on individuals' own perspectives. We sought to organize reported challenges using the biopsychosocial framework to capture the multifaceted nature of these challenges, identify unmet needs within specific domains and offer recommendations to improve biopsychosocial care for this population.

Methods

Participants and Procedures

This was a secondary analysis of data collected as part of a larger survey of individuals with chronic orofacial pain.²⁴ We recruited participants via a newsletter to members of the Facial Pain Association (FPA), a non-profit organization serving individuals affected by facial pain, between March and June 2021. To be included in this study, participants had to be adults living in the United States, have an ability to read and write in English at a 6th grade level, and report having nonmalignant facial pain of any kind for more than 3 months. Participants indicated their consent on an electronic form prior to completing a series of questionnaires. All study procedures were approved by the Massachusetts General Hospital Institutional Review Board and comply with the Declaration of Helsinki.

Three hundred and three participants responded to an online battery of questionnaires,²⁴ of which 260 responded to the single open-ended question we report on here: "What is the biggest challenge you face in managing your condition?" Participants typed their responses into a text box. Self-reported demographic and diagnostic information is detailed in [Table 1](#). We classified reported diagnoses based on the International Classification of Orofacial Pain, 1st edition (ICOP).⁴ Final diagnosis categories included trigeminal neuralgia, other trigeminal neuropathic pain, classical trigeminal neuralgia with concomitant continuous pain, persistent idiopathic facial pain, and other less common diagnoses (eg, myofascial pain, glossopharyngeal neuralgia). Additionally, 22% of participants reported multiple cooccurring diagnoses.

Data Analysis

We synthesized our findings utilizing a hybrid inductive-deductive thematic analysis approach.^{25,26} This methodological approach allows integration of data-driven codes with theory-driven ones based on the tenets of social phenomenology (ie, subjective perspective of individuals living in the world).²⁶ Our approach was deductive in the sense that we mapped findings onto biomedical, psychological, and social themes that we selected a priori based on the theoretical framework of the biopsychosocial model.²⁷ Our approach was also inductive in that we concurrently identified findings within each theme that emerged directly from the data. Specifically, we grouped and organized codes to allow novel findings within each a priori theme to develop. We defined a-priori themes based on the biopsychosocial model: 1) *biomedical* (ie, challenges relating to physical function and physiological aspects of injury), 2) *psychological* (ie, challenges relating to cognition, coping, emotion, and mental health or well-being) and 3) *social* (ie, challenges relating to interpersonal, socioeconomic, community and life participation factors).^{27,28}

First, 2 coders (BL and DS) separately reviewed and open coded 15% of responses (n = 39). The team (BL, DS, JG, and SB) then met to discuss and agreed on a set of common codes. The data analysis team consisted of two clinical and

Table 1 Participant Demographics

Variable	
Age, M (SD)	59.43 (26.16)
Gender, n (%)	
Male	33 (13.7)
Female	226 (86.9)
Race	
American Indian/Alaskan	1 (<1)
Asian	1 (<1)
Black	5 (1.9)
White	207 (79)
Multiracial	9 (3.5)
Ethnicity, n (%)	
Hispanic/Latino	13 (6.5)
Non-Hispanic/Latino	238 (91.5)
Diagnostic category, n (%)	
Trigeminal Neuralgia	130 (50.8)
Multiple diagnoses	58 (22.3)
TN2	21 (8.1)
TNP	18 (6.9)
PIFP	14 (5.4)
Other	11 (4.2)
None stated	8 (3.1)

Notes: TNP: Other trigeminal neuropathic pain; TN2: Classical trigeminal neuralgia with concomitant continuous pain, formerly called Atypical trigeminal neuralgia and trigeminal neuralgia type 2; PIFP: Persistent Idiopathic Facial Pain, formerly called atypical facial pain. Diagnoses included in “Multiple diagnoses” and “Other” diagnostic categories not listed elsewhere included migraines (n=7), myofascial orofacial pain (n=2), temporomandibular disorders (n=6), glossopharyngeal neuralgia (n=10), Burning Mouth Syndrome (N=3), occipital neuralgia (n=6) and diagnoses not specified in the ICOP (n=21).

research psychologists and two doctoral students in the fields of psychology and rehabilitation science. Next, the two coders reviewed another 15% of responses and met again to determine if any additional codes surfaced that were not previously conceptualized. Then, the two coders (BL and DS) coded all remaining responses and re-reviewed the first 30% of responses to ensure optimal fit to the final code list. Coders met again to discuss and resolve any discrepancies. Two members of the team (BL and JG) then met to review coded data, combine codes into broader parent codes, and identify sub-themes and representative exemplar quotes. We allowed partial overlap between the themes consistent with the view of the biopsychosocial model as a system of three interdependent factors, and in line with common practices in thematic analysis highlighting theme interconnectedness.^{29,30}

Results

We organized codes of the challenges participants reported into *biomedical*, *psychological*, and *social* themes, and identified subthemes within each of these deductive themes, presented in Table 2 with exemplar quotes. Figure 1 depicts the distinct and overlapping subthemes across the model. Below, we describe nuances as occurring in “some” instances to present findings that were neither very rare nor highly frequent (occurred more than three but fewer than 20 times).

Biomedical Challenges

We identified five subthemes within the *biomedical* theme including challenges with biomedical pain management, biological functions and related activities of daily living, medication side effects, sensory triggers, and physical

Table 2 Themes, Subthemes, and Exemplar Quotes

Theme	Subtheme	Exemplar Quotes
Biomedical	1 Medication Side Effects	<p>"If I take enough medicine, the pain is fine but my brain gets foggy"</p> <p>"The more effective medications affect my thinking and motor skills too much to use them."</p>
	2 Sensory Triggers	<p>"The colder weather and changes in barometric pressure. In the summer, it is air conditioning, especially when I come in from warmer weather."</p> <p>"My facial pain is aggravated by chemicals & fragrances."</p>
	3 Physical Symptoms of Stress/ Tension	<p>"Hemifacial Spasms contributing to my pain, as I'm constantly tense. Vicious cycle."</p> <p>"I'm so exhausted because no matter how good I get at ignoring the pain my body is still expending energy sending those high alert signals."</p>
	4 Biological Functions and Related Activities of Daily Living	<p>"Poor nutrition and oral care due to pain and inability to sleep leads to deteriorating health."</p> <p>"The hardest part is that my condition makes it difficult to talk for more than an hour or so without causing a lot of pain."</p>
	5 Challenges with Biomedical Pain Management	<p>"Excruciating burning"</p> <p>"I don't want to manage my condition, I want it fixed completely. I'm tired of being given pills that don't fix my problem"</p> <p>"I still suffer every second of everyday. There is no end, no real help, no cure & no hope of this horrible situation ever ending. That's the reality we live with. That is what we face every single day."</p>
Psychological	1 Anxiety	<p>"Worry about pain coming during a social situation."</p> <p>"I'm taking medication and I worry it will stop working."</p> <p>"The fear of it getting worse over time."</p>
	2 Depression	<p>"Not getting depressed and missing my old lifestyle."</p> <p>"There is nothing to look forward to because no one will fix me and no one cares."</p>
	3 Emotional Symptoms of Stress	<p>"Stress makes the pain worse and nothing makes it better."</p> <p>"Endless loop: Working long hours distracts from the pain but deepens the stress, which aggravates the pain."</p>
	4 Unpredictability/Uncertainty of Pain	<p>"Severe, unpredictable pain."</p> <p>"Fear of impending pain. Not knowing when it will be very bad."</p>
	5 Psych/Cog Aspects of Med Management	<p>"Constantly checking the time to see if I can take something else."</p> <p>"Currently, hoping that my body will continue to tolerate my high dosage of oxcarbazepine for as long as I need it to survive living with TN."</p>
	6 Positive Coping Strategies	<p>"Acceptance."</p> <p>"Disconnecting from my thoughts."</p>
Social	1 Social Relational	<p>"Sometimes I feel like I can't live a normal life. It's hard to make plans when I am unsure if I can do things. I feel isolated and sometimes, unsupported by some people around me. It's hard to understand pain, when you don't experience it."</p> <p>"A big challenge is also not being able to do things others do such as listen to certain types of music (often triggers pain)—with dating most people online LOVE music and it is stressful figuring out at what point do I let them know about this condition."</p>
	2 Experience with Providers	<p>"Doctors not believing how it affects me."</p> <p>"I have been all over the country in search of help but no one can actually pinpoint the exact location or cause of the injury."</p>
	3 Socioeconomics and Access to Care	<p>"The cost of prescriptions."</p> <p>"The roadblocks health insurance places to my accessing programs, medications, devices."</p> <p>"COVID has made it difficult to seek out medical care."</p>
	4 Roles and Responsibilities	<p>"Trying to be strong and 'normal' for my family. As a mom. Being able to make it go away so I can go back to work as a nurse. I want to take care of others again and not have people take care of me."</p> <p>"Trying to keep my pain level down while still moving around doing everyday household chores."</p>

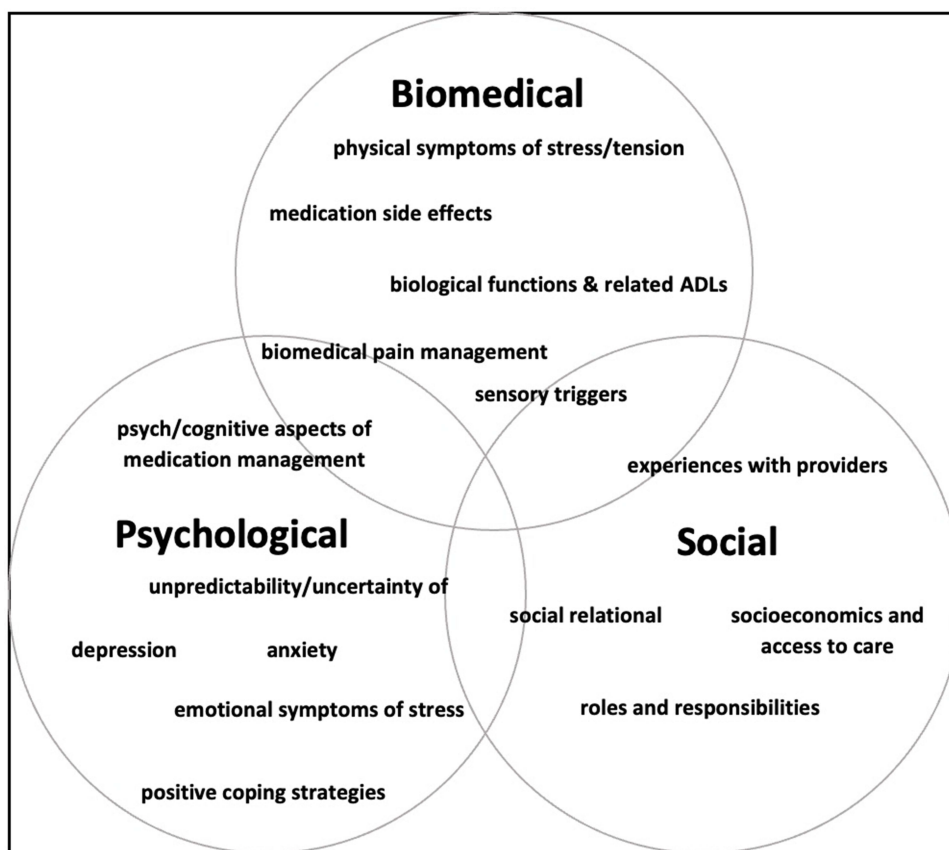


Figure 1 Biopsychosocial model: map of subthemes.

symptoms of stress/tension. Challenges with biomedical pain management were the most common subtheme, reported by a third of participants. Participants described challenges relating to finding effective treatments and solutions, as well as the severity, constancy, progression, and/or chronicity of their pain. Participants described the uncontrollability of pain, in that pain did not respond to medications or other treatments, or that once breakthrough pain occurred it was long lasting and difficult to resolve.

The second most common subtheme was biological functions and related activities of daily living which included difficulty eating, sleeping, speaking, maintaining hygiene, and other daily activities. Some associated their poor sleep and nutrition with overall deterioration of health. Several participants described speech and communication as major challenges. For example, one reported “I am the grunt master. Hard to talk and sometimes text.” When describing medication side effects, participants often reported facing a dilemma choosing between experiencing pain and facing cognitive challenges, foginess, fatigue, balance, dizziness, and motor issues caused by medication. Other medication side effects included allergies and problematic interactions between medications. Participants further noted challenges associated with sensory triggers of pain such as weather (eg, temperature and wind), and other aspects of the environment (eg, chemicals and fragrances). Two participants specifically described challenges with the typical climate in their home regions: fog in San Francisco, and cold in Minnesota winters. While sensory triggers are a hallmark of trigeminal neuralgia,⁴ participants in nearly all diagnostic categories identified environmental and sensory triggers as one of their greatest challenges. Challenges associated with physical symptoms of stress/tension included tense muscles, spasms, and high energy expenditure related to pain and resulting in exhaustion.

Psychological Challenges

We identified six subthemes within the *psychological* theme including anxiety, depression, emotional symptoms of stress, unpredictability/uncertainty of pain, psychological and cognitive aspects of medication management, and positive coping strategies (including resilience and mindfulness).

Challenges depicting anxiety/worry typically focused on either disease progression (eg, worsening of pain and function over time, medications becoming ineffective) or were more general worry about the future. The constant vigilance about pain management and avoidance of triggers caused some to “drive [themselves] crazy dwelling on it.” Challenges pertaining to anxiety sometimes cooccurred with challenges relating to the unpredictability of pain. Participants worried about flairs occurring at inopportune times, such as during social activities, or for those who have found some relief, when their breakthrough pain might return. One participant described “always wondering when the next shock is going to come.”

Participants also described experiencing difficulties related to depression symptoms such as hopelessness and negative thinking. Some described these symptoms in connection to grief and loss of their “old lifestyle” and changes in their identity as well as their perception of having “nothing to look forward to”. One participant indicated experiencing suicidal ideation in the past.

Issues related to psychological and cognitive aspects of medication management dominated participants’ lives, requiring them to constantly check their clock and medication schedule or monitor and revise dosage. Some experienced mood fluctuations as the effects of their medications/treatments waned resulting in feeling “miserable and often irrational”. Some were concerned for their body’s ability to tolerate high doses of strong medication “for as long as [they] need it to survive living with [their diagnosis]”.

Some reported that emotional symptoms of stress were their greatest challenge, typically in that it contributed to the cycle of worsening pain resulting in increased stress. Rarely, participants complemented the challenges that they identified with positive coping strategies including resilience, acceptance, and mindfulness, and described attempting to keep a positive mindset or “living day to day”.

Social Challenges

We identified four subthemes within *social* theme including roles and responsibilities (including home, community, and employment), experience with providers (competence of providers, differential diagnosis), social relational (including social isolation and social identity/other social challenges), and socioeconomics and access to care.

The most common sub-theme within the social domain was challenges related to roles and responsibilities. Some participants described challenges related to loss of work and described difficulty obtaining and keeping a job due to the disruptive and debilitating nature of pain. Some described how pain and avoidance of triggers impacted ability to complete home and community level responsibilities including chores and shopping/errands. Participants also described challenges in their ability to parent, spend time with family, and serve as caregiver to others.

Second most common were challenges regarding participants’ experience with providers. Participants found it difficult or “impossible” to find doctors with the knowledge and skills needed. Some expressed frustration at the lack of empathy and attention they received from providers. Others reported their difficulty with establishing a differential diagnosis and described traveling the country seeking answers.

Social relational challenges included social isolation, social activity, and identity. Participants expressed a sense of isolation due to living with an “invisible” illness. Others reported opting out of social engagements due to pain or fear of onset of pain. Participants reported feeling misunderstood by family, friends, and others who do not live with chronic pain. Some reported challenges with making plans, dating, maintaining relationships, and generally “being normal.”

Participants also noted challenges related to socioeconomics and access to care. Some participants described struggling to live on reduced income from disability and social security. Several experienced difficulty affording their medications and/or lacked adequate insurance coverage for programs and treatments (eg alternatives to pharmacological treatments such as supplements, therapies, and acupuncture). Additionally, the societal impact of the COVID-19 pandemic impacted access to orofacial pain care due to barriers such as cancelled appointments and surgeries, and limited seating in pharmacies.

Discussion

We conducted the first qualitative thematic analysis of individuals’ perceived challenges due to chronic orofacial pain. We utilized a hybrid inductive-deductive approach and synthesized findings using a biopsychosocial framework in order

to promote a comprehensive understanding of challenges experienced by impacted individuals. We summarize findings and offer specific recommendations for each challenge in the sections below.

We identified *biomedical* subthemes including challenges with biomedical pain management, medication side effects, biological functions and related activities of daily living, sensory triggers, and physical symptoms of stress/tension. The most frequently identified sub-theme was challenges with biomedical pain management. Individuals often described a lengthy and frustrating search for pain relief, and many failed treatment attempts. This is consistent with previous research on efficacy of treatments for chronic orofacial pain indicating a success rate of less than 25%.¹² Participants reported ubiquitous use of pharmacological treatment with unpleasant and debilitating motor, cognitive, and mood related side effects. Consistent with previously published studies,¹⁵ participants identified pervasive difficulty with biological functions and related activities of daily living which ultimately negatively impacted overall health and wellness. Additionally, participants reported challenges with sensory triggers and described physical symptoms of stress/tension as both a cause and effect of their pain. To address the aforementioned challenges with medication side effects, providers may consider integrating discussion of these common side effects into standard care to empower patients to make conscious choices about the cost benefit of their medications. Providers may also consider opioid rotation, changing administration route,³¹ dietary changes (increased fiber),³¹ or complementary treatments such as acupuncture³² to help manage medication side effects. To address challenges with biological functions and related activities of daily living, providers should include assessment and treatment of sleep, communication, nutrition, or other aspects of self-care to optimize patients' health and function despite their pain.³³ Patients may benefit from referrals including occupational therapy for modifications to activities of daily living,³⁴ speech language pathology for treatment of speech, communication, and swallowing function, and nutrition and dietetics to address patients' nutritional needs in the setting of odynophagia. Additionally, patients who experience sensory triggers could benefit from counseling to identify their unique environmental triggers, develop predictive awareness to avoid them, and establish a toolkit of strategies to manage them. Finally, patients who experience physical symptoms of stress/tension could benefit from pain-informed mind-body interventions to develop skills around interrupting patterns of stress, tension, energy expenditure, and pain.³⁵

We identified *psychological* challenges including anxiety, depression, emotional symptoms of stress, unpredictability/uncertainty of pain, psychological and cognitive aspects of medication management, and positive coping strategies (resilience/mindfulness). Participants described the interplay of depression, anxiety, and general mental suffering with the severity of their pain condition. They additionally mentioned the unpredictability of their pain as a source of anxiety which impacted their ability or willingness to participate in social activities and work. Results are consistent with previous work indicating that psychological factors can play a role in the manifestation of chronic orofacial pain.^{9,36} Several psychosocial interventions have demonstrated feasibility and potential utility of use among people living with chronic orofacial pain including: Cognitive Behavioral Therapy, relaxation, and biofeedback.^{36–40} However, prior research notes limited discussion between providers and patients of such opportunities, resulting in limited access to these interventions.⁹ Our results indicate a need for accessible programs to be more commonly embedded in standard care to address the specific psychological experiences of people with chronic orofacial pain. Providers who have contact with people with orofacial pain, particularly those directing care plans (dentists, neurologist, and primary care physicians) should be aware of these psychological challenges and screen patients for emotional distress and make referrals to psychosocial care when indicated.

We identified subthemes within the *social* theme including social relational challenges, roles and responsibilities, experiences with providers, and socioeconomic and access to care. Our findings are consistent with prior research that suggests that experiences of not being understood by friends, family, and society at large are common among people living with all types of chronic pain.⁴¹ Participants in this study linked their isolation and change in social roles and responsibilities to feelings of depression and overall decreased participation in society contributing to a troubling cycle of isolation, hopelessness, grief, and changes to identity roles. To address these social challenges, patients with orofacial pain may benefit from dyadic and systemic approaches to treatment which involve spouses and family members. Clinicians may additionally provide patients with information about resources such as orofacial pain support groups, online forums, and orofacial pain advocacy organizations (eg, the Facial Pain Association).

Participants emphasized their difficult experiences with providers and navigating care (eg, distress around not being “believed”, difficulty obtaining a definitive diagnosis, and perceived lack of knowledgeable providers). These findings are consistent with prior research on chronic orofacial pain^{9,42} and suggest a need for more training and resources for providers who manage these cases. Trainings could include building communication skills and strategies for complex cases, and raising awareness of the prevalence of idiopathic presentation of orofacial pain. Difficulty accessing care due to the cost of treatment and insurance coverage issues is consistent with the broader literature on disparities in access to care, and may be particularly pronounced for those who are uninsured, experiencing financial insecurity, or who have less financial resources.⁴³ Patients could benefit from increased access to social work to assist in navigating financial and social resources and establish vocational accommodations when indicated. This may also inform potential changes in policy such as reduced cost for effective pharmaceuticals, and expansion of coverage to evidence-based complementary therapies.

Overall, these results offer a novel perspective emphasizing the co-occurring and interdependent challenges associated with chronic orofacial pain and underscore the importance of assessing and addressing biomedical, psychological and social aspects of living with orofacial pain. As depicted in [Figure 1](#), some of the subthemes identified fall close to the intersection of multiple domains of the biopsychosocial model, suggesting notable implications for treatment planning and delivery. Challenges associated with chronic orofacial pain may be distributed across a bio-psycho-social continuum, and challenges in one domain may produce challenges in another domain. This interplay has implications for case conceptualization and intervention. For example, when prescribing medications for pain management, providers should be aware of psychological and cognitive factors important to successful medication management and provide education and resources as needed.

This study has several strengths. First, we included a relatively large number of participants from a national association with a geographically broad area, which enabled us to gather diverse perspectives comprehensively capture a wide range of challenges associated with chronic orofacial pain across individuals. Second, we included individuals with a variety of orofacial pain diagnoses. While most previous research on orofacial pain silos participants based on their different diagnoses, the current findings reveal more similarities than differences in challenges experienced among the diagnoses represented in our sample. This supports a transdiagnostic approach to management of orofacial pain which may increase scalability of treatments for this population.⁴⁴ Third, this paper focused on patients’ perspectives and lived experiences, which are often overlooked in quantitative literature in general, and in orofacial pain research in particular, and are important to inform treatment priorities.

Limitations

Several limitations of this study should also be considered. First, participants responded by typing in a text box as part of an online survey. As such, we may have not gathered as in-depth responses as those gathered by other qualitative methods, such as semi-structured interviews. Second, while our sample included individuals with several of orofacial pain conditions, approximately half of the sample reported trigeminal neuralgia as their primary diagnosis. All demographics were self-reported, including pain diagnosis, which may be limited by participants’ awareness of their diagnosis or willingness to disclose. Our sample was predominantly white (79%). Thus, the perspectives of some diagnostic and racial identity groups may be underrepresented in this sample. This is of particular importance given the difference in pain outcomes and treatment disparities between ethnic and racial groups.⁴³

Conclusions

Individuals with chronic orofacial pain face a range of challenges across the biopsychosocial continuum. Multimodal programs for people with chronic orofacial pain may be particularly suitable for targeting these heterogeneous challenges. Consideration of biomedical, psychological, and social factors in the assessment, referral, and treatment of individuals with chronic orofacial pain holds potential to considerably improve care for this population. Further research is warranted to clarify differential challenges associated with specific orofacial pain conditions.

Data Sharing Statement

The data that support the findings of this study are available on request from the corresponding author.

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Disclosure

Authors declare that they have no conflicts of interest.

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